

Barriers Direct Care Workers Face

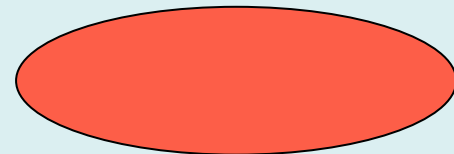
Cost of
Caregiving

Veronica Faison

Who Are Direct Care Workers?

- Direct care workers provide long-term care or support in the home (home health and personal care aides), in nursing homes (nursing assistants) or in residential settings.
- Nationally, and especially in NY, these workers are overwhelmingly women (87%) predominantly people of color (77%) and disproportionately immigrant (58%).
 - In compara, nationally - 84% are women, 67% are people of color, 32% are immigrants)
- Workers paid between \$16 and \$18 per hour
- But part-time hours also drive low annual earnings. Many direct care workers are not offered full-time employment: 46% of home care workers, for example, work fewer than 35 hours a week. And overall, home care workers have a median annual income of just \$21,889

How does low wages and poor job quality impact direct care workers?



- Over 40% rely on Medicaid, 10% uninsured
- Low wages impact ability for these workers to care for their families
 - Many workers underpaid live in poverty or close to poverty; many of these same workers have children
 - Direct care workers: 36% live in or near poverty
 - 1. In NY, 33% are in low-income households
 - One-third live with children under 18
 - 25% provide family caregiving for older adult (like a parent)
- Drives workers out of their jobs
 - Faced with economic precarity and low job quality – turnover rates are high - home care workers face 80% annual turnover
 - Already cannot meet the growing need for long-term care workers as people face disability and aging

Importance of Medicaid

Direct care workers are doubly reliant on Medicaid

- Medicaid is the largest payer of long-term care, including home and community-based care
- The large share of this pool goes to direct care worker wages

Because of low wages, direct care workers rely on Medicaid for insurance, especially women workers

- 27% of women direct care workers under 65 rely on Medicaid coverage themselves and 13% are uninsured
- Over 40% of direct care workers rely on public benefits (which includes SNAP)



Attacks on Medicaid

- Large cuts to Medicaid (\$1 trillion from low-income families!) will be felt on every person, and will make it harder to survive as a direct care worker
- When states face federal shortages in the form of Medicaid cuts – so-called optional “HCBS” services are at risk of the chopping block, despite being central to the lives of millions of disabled people and older adults
- **“Work requirements ” especially impact working people working inconsistent hours or non-traditionally structured roles**
- OBBA makes it more difficult for immigrants to access Medicaid - which also disproportionately impacts direct care workers - as immigrant workers already face outsized threats to their communities and families

What Can We Do?

1

Supporting laws that protect direct care workers rights to a living wage

2

Challenging proposals to strip back investments in long-term care due to budget shortfalls

3

Uplift the importance of protecting immigrant workers, who are vital to our communities

THANK YOU

The Strain of Unpaid Caregiving in New York: Empire State Poll Results

Zoë West, Worker Institute, Cornell ILR School

The 2024 Empire State Poll

- Annual survey across NYS administered by the Cornell University ILR School
- Questions on labor and employment issues and other top concerns
- In August 2024, the ESP surveyed 2,686 respondents across New York State

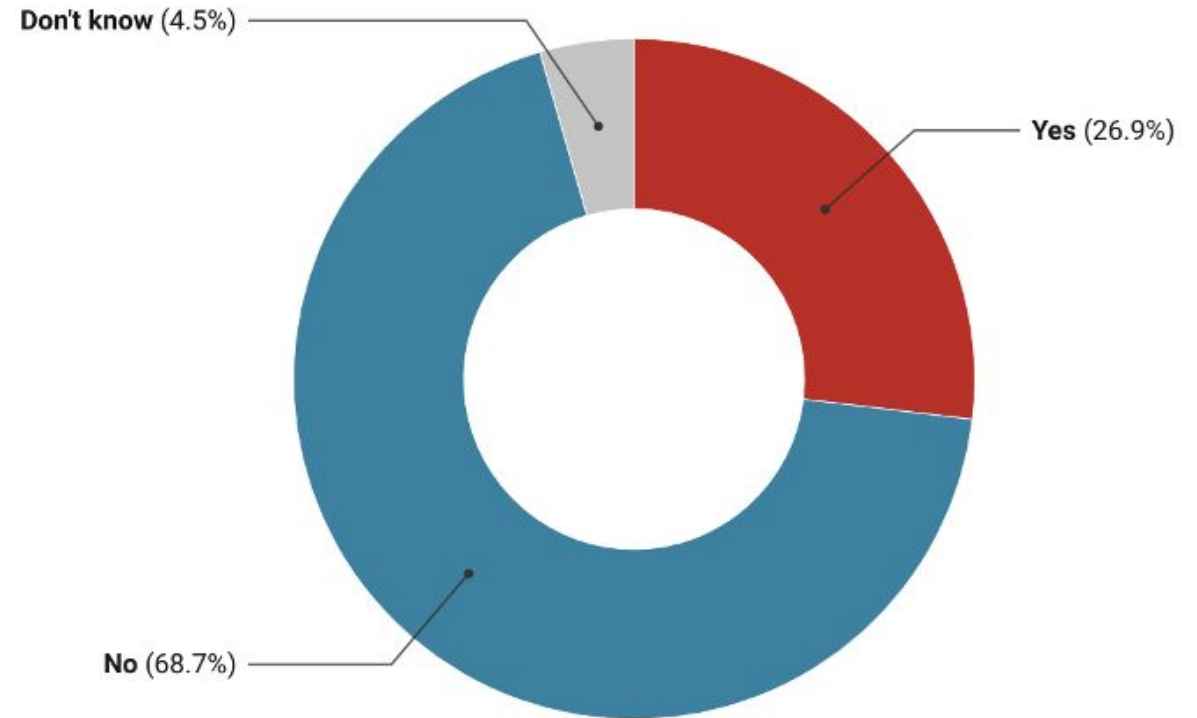
Over one third of women and over one quarter of men were caring for children, adult family members, and/or friends or neighbors.

- **29.9% were providing unpaid caregiving** for children, adult family members, and/or friends or neighbors on a regular basis.
- **33.7% of women** respondents were providing unpaid caregiving support
- **26% of male** respondents were providing unpaid caregiving support
- People of color across all racial/ethnic groups were more likely to report providing unpaid caregiving support
- People with disabilities were more likely to be providing unpaid caregiving support, at 39.3% (2023 data)

- **Child care** was the most common form of caregiving reported
 - 18.7% of respondents who reported caring for children
 - 13.7% caring for adult family members
 - 4.1% caring for friends or neighbors
 - “Sandwich caregivers” made up 4.5% of respondents.
- Women were significantly more likely to be caring for children than men (21.9% vs. 15.4%)
- Black (17.1%), Asian (16.8%) and Hispanic (14%) respondents were all more likely to be providing unpaid caregiving support to adult family members than white respondents (11.9%).

More than a quarter of all caregiving respondents said their caregiving responsibilities made it difficult to maintain a job.

Have your unpaid caregiving responsibilities made it difficult for you to maintain a job?

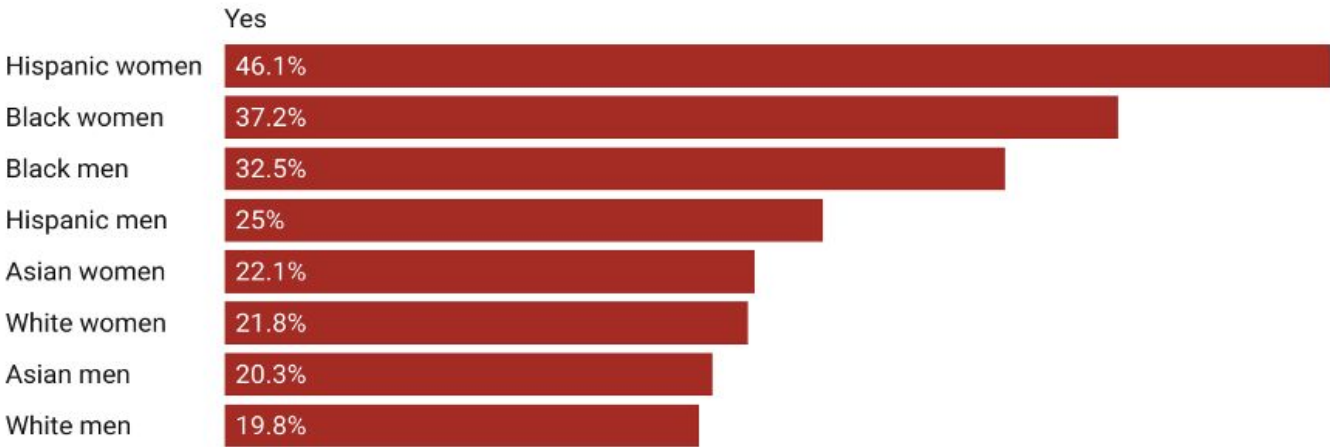


Universe: Respondents who reported unpaid caregiving responsibilities [n=805 weighted observations]

Source: 2024 Cornell University ILR Empire State Poll • Created with Datawrapper

Hispanic and Black respondents — women in particular — reported this challenge at significantly higher rates.

Have your unpaid caregiving responsibilities made it difficult for you to maintain a job?



*Universe: Respondents who reported unpaid caregiving responsibilities [n=752 weighted observations]
Subsamples: Hispanic women [n=105], Black women [n=72], Black men [n=47], Hispanic men [n=56], Asian women [n=29], White women [n=224], Asian men [n=39], White men [n=180]*

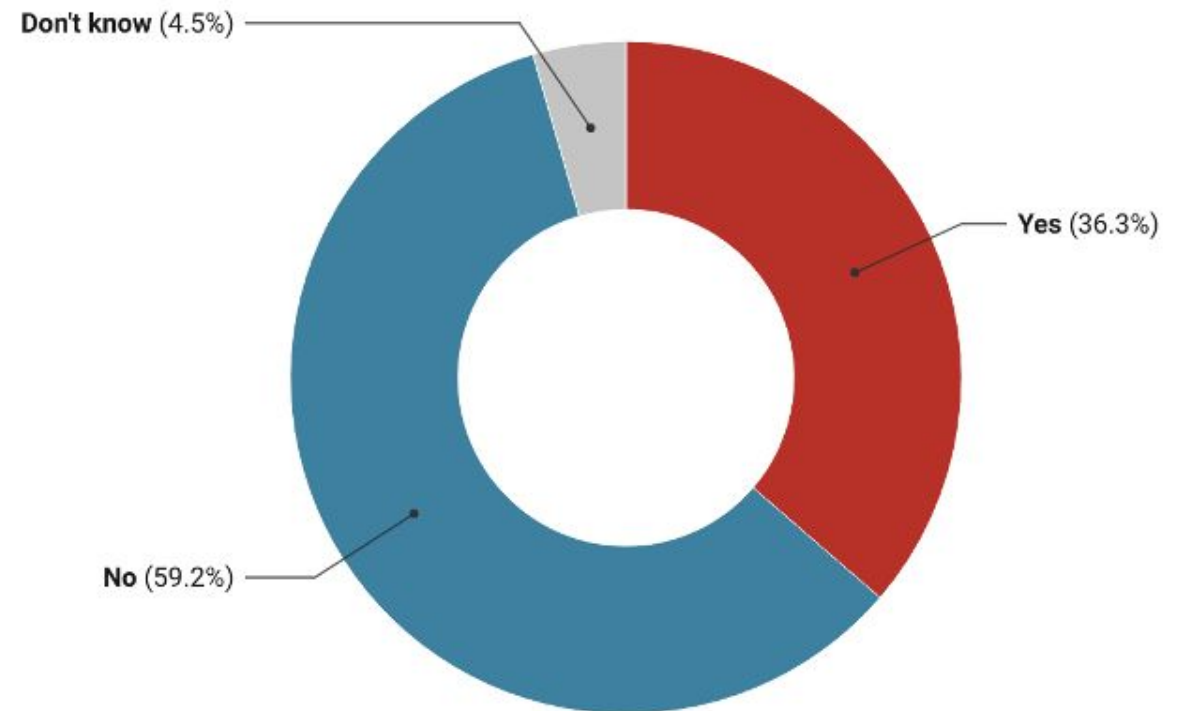
Source: 2024 Cornell University ILR Empire State Poll • Created with Datawrapper

Unpaid caregiving made it difficult for respondents to maintain a job across all forms of caregiving.

- **30.4%** of those caring for both children and adult family members
- **28.1%** of those caring only for adult family members
- **25.6%** of those caring only for children
- **21.7%** among those caring for friends and/or neighbors

More than one third of caregiving respondents reduced their paid work due to their unpaid caregiving responsibilities.

Over the past year, has the unpaid amount of time you spend on caregiving support for children, adults, or other loved ones caused you to spend less time doing paid work?

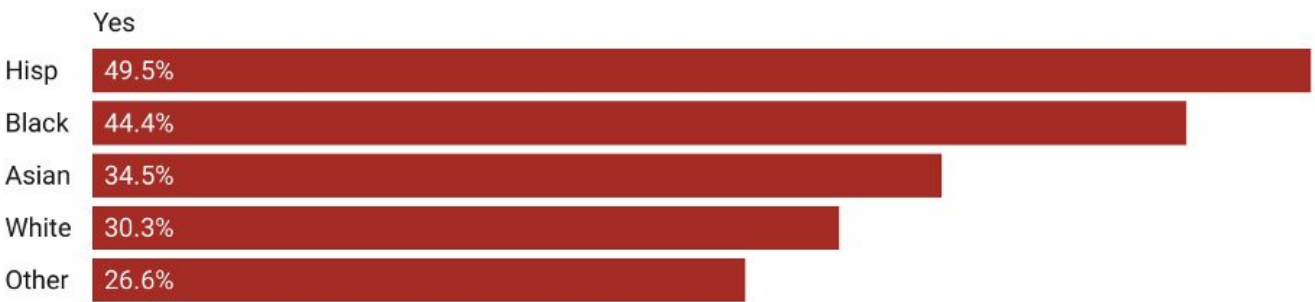


Universe: Respondents who reported unpaid caregiving responsibilities [n=805 weighted observations]

Source: 2024 Cornell University ILR Empire State Poll • Created with Datawrapper

People of color were significantly more likely to report that unpaid caregiving caused them to reduce their time spent doing paid work.

Over the past year, has the unpaid amount of time you spend on caregiving support for children, adults, or other loved ones caused you to spend less time doing paid work?



*Universe: Respondents who reported unpaid caregiving responsibilities [n=804 weighted observations]
Subsamples: Hispanic [n=161], Black [n=119], Asian [n=69], White [n=404], Other [n=52]*

Source: 2024 Cornell University ILR Empire State Poll • Created with Datawrapper

Among those who reduced their paid work due to unpaid caregiving, the top reason was that care was not affordable — this was especially true for those caring for children.

Was the decision to spend less time doing paid work primarily because...?



Universe: Respondents who reported spending less time doing paid work due to their caregiving responsibilities for children [n=235 weighted observations]
Source: 2024 Cornell University ILR Empire State Poll • Created with Datawrapper

New Yorkers hiring home care workers (2023)

- 29% of respondents said they or a loved one had tried to get home care services at some point
 - *41% of respondents with disabilities*
- Over 22% of respondents had hired someone to provide care or cleaning services in their home in the past year.
 - *Among those, people with disabilities were twice as likely to have hired someone to provide home care services.*

New York Care Workers:

The Weight of Stress and Unpaid Caregiving

2023 Empire State Poll Data

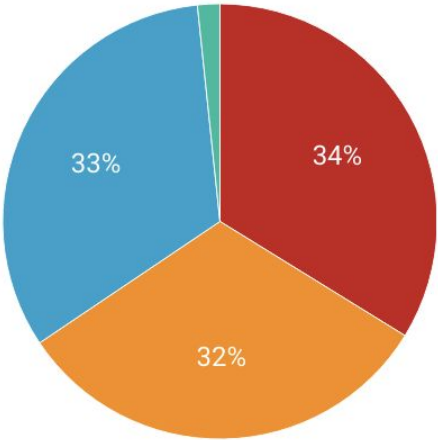
Paid care workers made up over one third of the working population of ESP respondents.

- **“Healthcare”** — work in the healthcare field
- **“In-Home”** — work as home care workers or as domestic workers (including nannies and house cleaners)
- **“Facility”** — work in early childhood education, childcare, elder care, disabled care, or social services (outside of the home)
- **“Care workers”** includes all of the above, as well as those who indicated that they work in an “other” care economy job

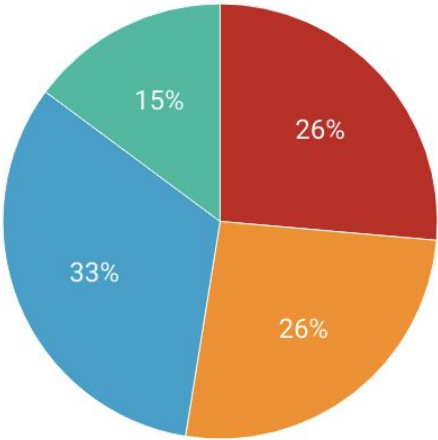
In-home care workers reported experiencing stress at work more frequently, with 66% reporting medium or high frequency of stress.

Frequency of Stress at Work

- High
- Medium
- Low
- Never



In-Home Care Workers



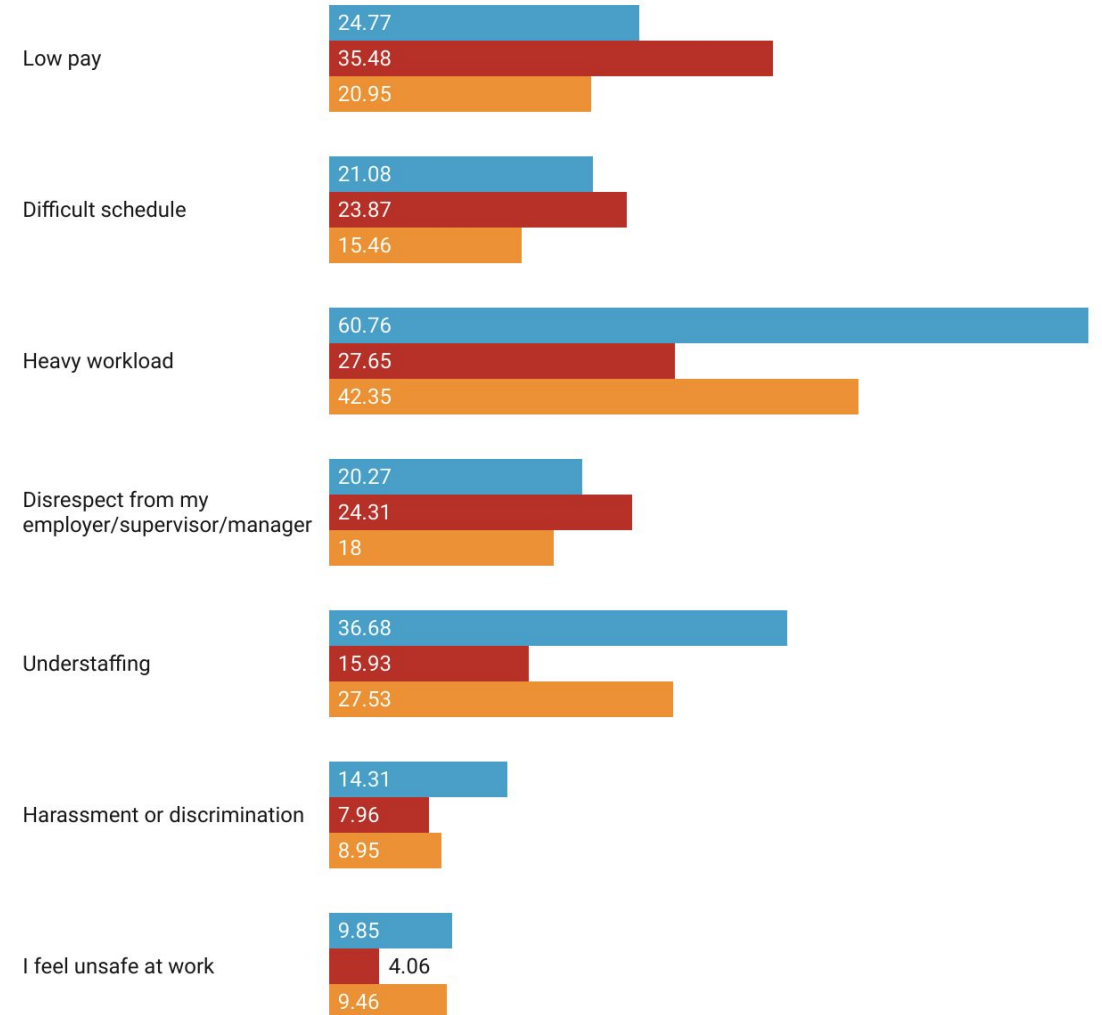
Working Population

Source: Empire State Poll 2023 • Created with Datawrapper

- In-home care workers were more likely to report **low pay and difficult schedules** as sources of stress.
- **Disrespect from employers, managers, and supervisors** was reported as a source of stress at higher levels across healthcare, in-home, and facility workers.
- Healthcare and facility care workers were nearly twice as likely to report **feeling unsafe at work** as a source of stress, compared with the general working population of respondents.

Sources of Stress at Work

Healthcare In-Home Facility

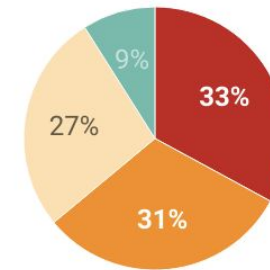
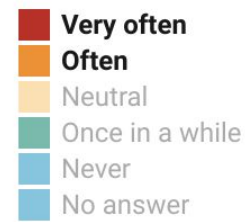


Care workers generally reported a **greater impact of stress and burnout** compared to the working population.

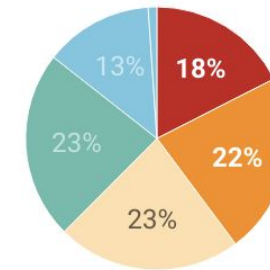
40% of care workers said job stress and/or burnout makes it difficult to take care of themselves and/or spend time with people they care about *often* or *very often*.

Stress and burnout had a **particularly heavy impact on in-home care workers** in this regard (64%).

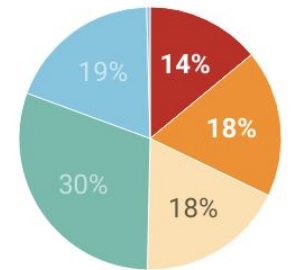
Impact of Stress and Burnout



In-Home Care Workers



All Care Workers

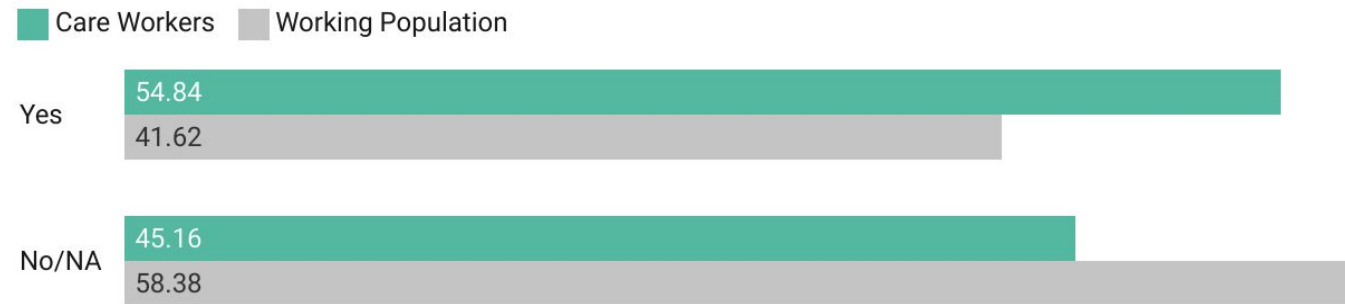


Working Population

Source: Empire State Poll 2023 • Created with Datawrapper

In addition to providing care as their *paid* work, care workers were also more likely to bear responsibility for unpaid caregiving in their personal lives.

Unpaid Caregiving



Source: Empire State Poll 2023 • Created with Datawrapper

**Recent changes and cuts
threaten to sharply
aggravate the care crisis.**

THANK YOU

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Home Care in New York After OBBBA

Fiscal Policy Institute

10/29/25



The Scale of Home Care in New York

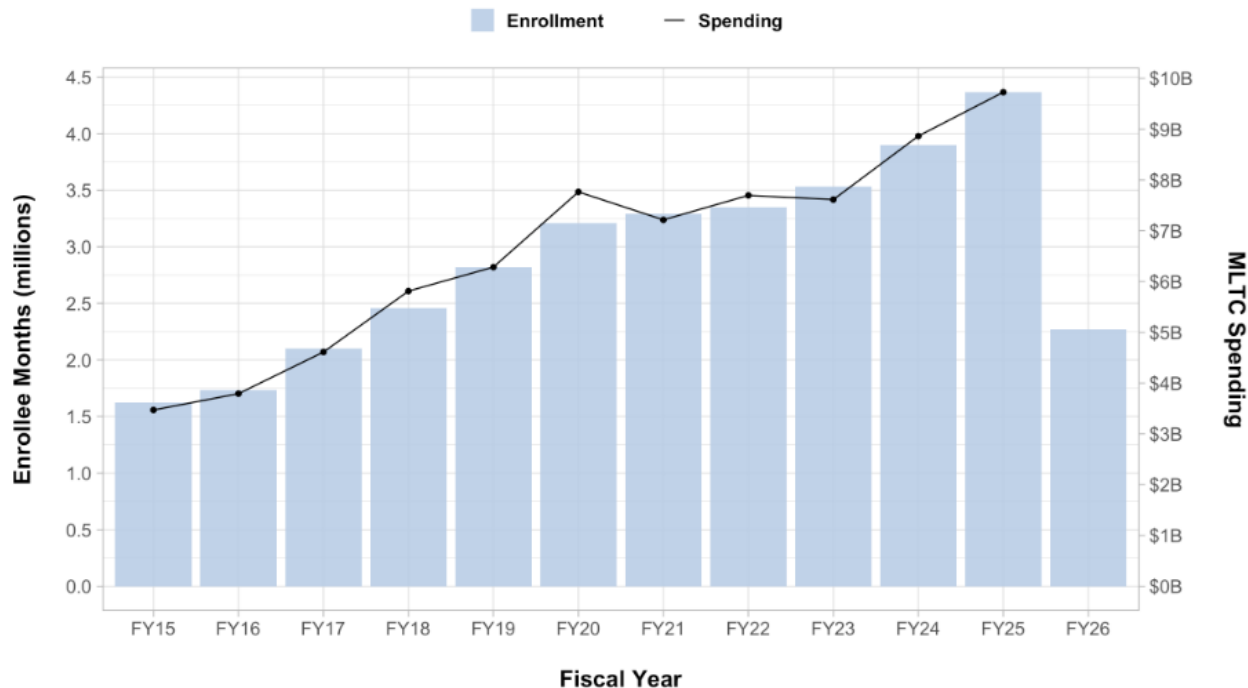
- Largest employment category in New York
- Expenditure in the major MLTC program grew from:
 - 2018: \$6B
 - 2023: \$20B
- Average expenditure per MLTC enrollee is ~\$60,000 / year.
- Enrollment has grown steadily for a decade but seems to be flattening at around 400k.



Growth of MLTC

Medicaid Managed Long Term Care Enrollment and Spending, by Fiscal Year

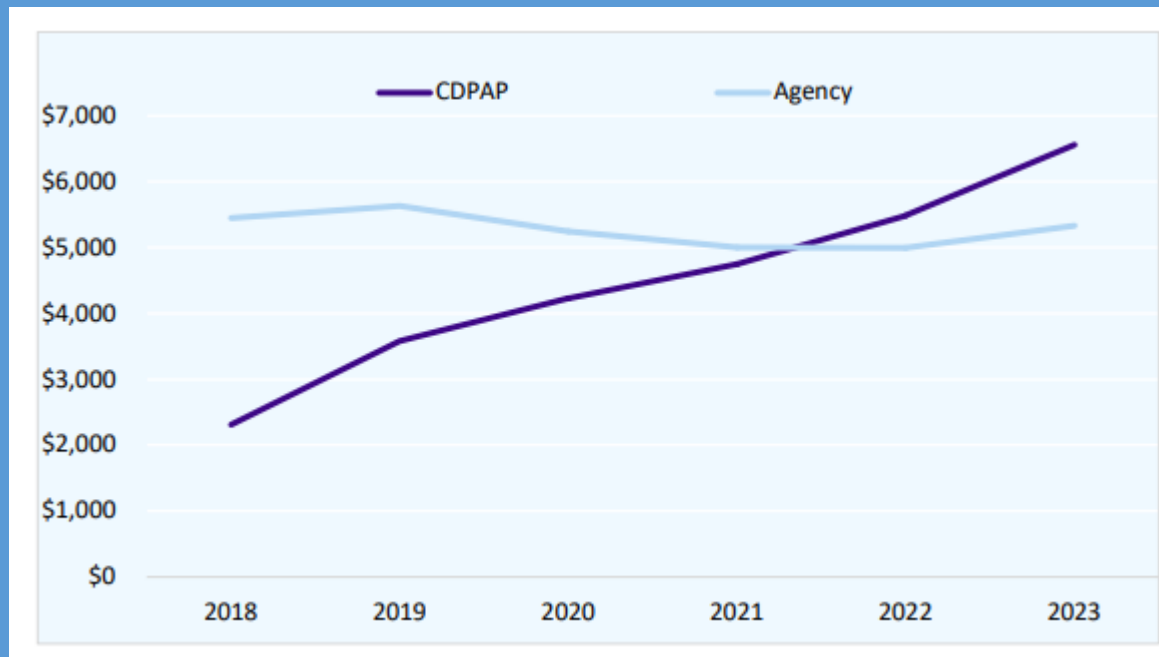
New York State (Since April 2014)



Sources: New York State Department of Health Medicaid Managed Care Enrollment Reports, and Medicaid Global Spending Cap Updates
Data as of: October 29, 2025



Growth of Family Caregiving





Progress on Wages and Benefits

- NYS has a legal minimum wage and benefit
- Substantial increase in wages and benefits:
 - 2010: \$10/hour with \$4.09 for benefits (NYC agency)
 - 2025: \$19.10 / hour, \$4.09 for benefits (NYC agency)
- Benefits spending often subject to employer wage theft



Myth of Nursing Home Savings

- Many advocates argue that home care saves money, since it replaces nursing home care.
- This can be true in specific cases but in general expanding access to home care costs money on net.
- Many people use paid Medicaid home care who would not be in a nursing home if this care didn't exist. (Instead they'd be receiving unpaid care or going without.)
- It is important to recognize that expanding home care generally shifts the social burden of elder care onto the state budget (which is good!) rather than replacing institutional care.



A Changing Industry Structure

- Before 2011: Industry dominated by downstate, nonprofit, unionized employers.
- 2011-2025:
 - Managed care
 - Growth of fragmented, for-profit, non-union employers in both agency and consumer-directed models
- Post-2025:
 - Continued fragmentation in agencies
 - Single for-profit fiscal intermediary for consumer directed workers.



Impacts of OBBBA

- OBBBA does not directly impact LTSS eligibility
- MASSIVE budget crunch will put tremendous pressure on state Medicaid budget
- How can the state cut spending?
 - State already moving to restrict eligibility (ADLs)
 - Likely to squeeze future rate increases
 - New CDPAP structure may restrain enrollment
- Benefit impact for workers:
 - Many (most?) home care workers rely on Medicaid and other low-income state programs
 - Eligibility changes will make this harder, especially for immigrants.



Taking Stock of the Past 10 Years

- NYS home care policy has been characterized by:
 - Willingness of policymakers to (grudgingly) accept growing enrollment and unit cost.
 - Delivery system increasingly full of for-profit middlemen.
 - Substantial shift to paid family caregiving.
 - Continued access challenges for elderly and disabled.
 - Continued burden of unpaid caregiving.



Failures of Our System So Far

- Despite (by national standards) very high spending, our home care system has not fully delivered on:
 - Providing good jobs
 - Providing easy access to home care
 - Relieving the burden of unpaid care



Looking Forward

- Do we need different models of care and compensation for family caregivers vs. others?
- Do we need to better address the spectrum of needs?
- Is HCBS delivering on its promise to integrate elders and disabled people into the community?
- Are there more community-oriented approaches (in senior housing, adult day care, naturally occurring retirement communities) that might provide better jobs and better care?
- Medicaid home care is an individual entitlement, but policy needs to be grounded in communities.



Calls to Action

- Think about need for care as a spectrum, policy solutions along the spectrum. (Against the medical model.)
- You can't get around addressing industry structure and organizing workers.
- Care is human labor – the test of a program is how much money goes to the worker.
- Give up on employer-sponsored healthcare.
- Fight eligibility cuts. Tax the rich!
 - The state can and should protect its home care entitlement.