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**Testimony to the New York State Legislature
Joint Hearings of the Senate Finance and
Assembly Ways & Means Committees**

2026-2027 Executive Budget

Topic: Health/Medicaid

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Thank you, Chair Krueger and Chair Pretlow, for the opportunity to provide testimony on the Fiscal Year 2026-2027 Executive Budget (proposed Budget). CELJ has been serving the Western New York region for over 40 years, providing free civil legal services to older adults, persons with disabilities, and low-income families. CELJ's primary goal is to use the legal system to assure that individuals may live independently and with dignity. CELJ also advocates for policy and systems change, particularly in the areas of housing, elder abuse prevention, nursing home reform, and consumer protection. Currently CELJ provides full legal representation in ten counties of Western New York.¹ CELJ's Free Senior Legal Advice Helpline is open to all of New York State. CELJ operates a main office in downtown Buffalo, with three additional offices in Cattaraugus, Chautauqua, and Niagara counties.

The proposed Budget sets forth to create a stronger, safer, more affordable New York. However the Budget does not do this for every New Yorker. Older adults and persons with disabilities are largely absent from the Budget. Older adults and persons with disabilities are under direct and constant threat by the federal administration whether through H.R.1 or policies that seek to push them into institutionalized settings. Older adults and persons with disabilities need a budget that promotes and supports independence, autonomy, and dignity. This means bringing affordability to people who live in nursing homes, demanding quality of care in long-term care settings, and supporting policies that promote community-living.

The Legislature must fight for a Budget that not only views and includes older adults and persons with disabilities as a part of the community, but ensure that all persons, regardless of their age, disability, race, geographic location, and income are able to age with independence, dignity and safety. New York State must take measures that ensure every New Yorker can thrive.

¹ Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Livingston, Niagara, Orleans, Steuben, and Wyoming Counties

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- I. [Support Actions that Promote Autonomy, Dignity and Access to Quality in Nursing Homes and Adult Care Facilities](#)
 - A. **Increase the Personal Needs Allowance for Nursing Home Residents**

CELJ strongly urges the Legislature to **fight for the people who live in nursing homes and include an increase in the Personal Needs Allowance (PNA) in the Budget.** The PNA is the amount of money, **currently \$50 per month**, nursing home residents are allowed to keep from their Social Security or other income to pay for essential personal items not covered by Medicaid. This amount was **set in 1988 and has never been increased**, despite nearly four decades of inflation. Adjusted for inflation, **\$50 in 1988 would be approximately \$140 today.** The spending power of the \$50 PNA has been eroded and resident quality of life is being actively harmed.

Medicaid covers room and board, nursing care, and routine services. It does not pay for the personal items that make life dignified and humane: a haircut, properly fitting clothing, a phone, quality toiletries, a card for a grandchild, or the ability to participate in community or religious life. For many residents, the PNA is their only source of personal income, yet it forces them to choose between the most basic needs and any semblance of personal autonomy.

Each year, Social Security provides cost-of-living adjustments (COLAs) intended to help older adults keep up with rising costs. However, nursing home residents never see these increases. Instead, their COLAs are captured by the nursing home as part of their Net Available Monthly Income (NAMI), leaving residents just as poor as before while operators receive increased revenue from COLAs. At the same time, the State has repeatedly increased payments to nursing home

operators without ensuring that any of those funds directly improve resident quality of life and care. The ‘trickle-down effect’ of the increases going directly to the operators does not work and has not benefited residents.

In Western New York, we have seen operators cut costs on a variety of items, choosing to purchase the cheapest most uncomfortable items with no options for the residents, including briefs, personal care items and food. One nursing home in Western New York for example has stopped providing even the smallest generic can of soda for mealtimes. If residents want a beverage other than milk, juice, or water with dinner, they must use the vending machine.

The human consequences of this policy failure are well-documented and not new. Residents have died waiting for the State to stand up and increase the PNA,² and continue to speak out³ for change.⁴ Most recently as opinion writers in both the *Times Union*⁵ and *The Buffalo News*,⁶ explaining \$50 a month is not a benefit, it is an insult to older adults who worked their entire lives and now spend their final years institutionalized and financially controlled by the State.

In 2024, in partnership with the NYS Office of the Long Term Care Ombudsman (NYS LTCOP) over 1,200 impact statements were collected by nursing home residents, family members, and supporters. The statements described what the \$50 PNA does, and does not, allow them to do.. Residents reported being unable to afford haircuts, phone service, transportation to religious services, or small gifts for loved ones. Enclosed are a summary of the impact statements and a breakdown of the statements by regional LTCOP (if known).

This year, the NYS LTCOP, in partnership with residents, **circulated a petition and obtained over 7,000 signatures urging the State to increase the PNA.**⁷

New York has rightly enacted reforms to improve nursing home staffing, safety, and oversight. But resident dignity and quality of life have been left out of the budget conversation. **Increasing the PNA, and indexing it to inflation, is one of the most immediate, direct actions the Legislature can take to restore autonomy, dignity, and basic humanity to nursing home residents.** Other states have recognized this injustice: the majority allow higher PNAs, some as high as \$200 per month, while New York lags far behind.⁸

CELJ supports A.2048/S.4744A that would the personal needs allowance to \$200 and require an annual adjustment reflecting the latest consumer price index. However, any increase, along with an annual adjustment, would be a positive improvement for residents.

² Neff Roth, A., “Life Well Lived; a Quest Unfulfilled; Local Advocate for Medicaid Allowance Increase Dies at 81”, June 29, 2018. <https://www.uticaod.com/story/news/2018/06/29/life-well-lived-quest-unfulfilled/11630044007/>

³ <https://www.youtube.com/watch?v=Ik3a0EzCIWE>

⁴ Jon Harris, “It’s hard to live on \$50 a month’: ursing home residents blast outdated spending allowance”, Buffalo News, Jan. 31, 2026. [NY nursing home residents: 'Hard to live on \\$50 a month'](https://www.buffalonews.com/news/local-news/2026/01/31/ny-nursing-home-residents-hard-to-live-on-50-a-month/)

⁵ Deborah E. Leary, “Commentary: Could you cover personal expenses on \$50 a month? Neither can nursing home residents.”, Times Union, Jan. 28, 2. <https://timesunion.com/opinion/article/new-york-personal-needs-allowance-medicaid-21317894.php>

⁶ Betty Ealy, “Another Voice: New York must increase the personal needs allowance for nursing home residents.”, Buffalo News, Jan. 16, 2026. https://buffalonews.com/opinion/article_60bffaab-b7ac-49be-a3d6-7dab723dab4a.html

⁷ <https://aging.ny.gov/raise-personal-needs-allowance-pna>

⁸ <https://theconsumervoicework.org/news/fact-sheet-what-is-personal-needs-allowance-pna-by-state-chart/>

People who live in nursing homes deserve more than survival. They deserve choice, connection, and dignity. **We urge the Legislature to include a meaningful increase to the Personal Needs Allowance, with annual cost-of-living adjustments, in this year’s State Budget.**

B. Reject Executive Budget Proposal HMH Part N subpart B and Other Actions and Efforts that Weaken Essential Staffing Standards in Nursing Homes

While there are nursing home operators who do place resident care and safety at the forefront of financial decision-making, too many do not.⁹ In 2021-2022 the State enacted a variety of reforms to address long-standing failures and improve the quality of care for all residents. Enforcement of these reforms must be fully implemented and strengthened. The opposite however is happening and reforms are being attacked through litigation and legislation, with a goal to weaken or repeal. The Legislature must reject actions that will weaken these essential laws.

CELJ strongly opposes and urges the Legislature to reject the Executive’s proposal to authorize certified medication aides in nursing homes. While promoted by supporters as a no-cost strategy to address staffing concerns, if implemented the quality of care in nursing homes will further decline and resident health and safety will be adversely affected. Resident acuity has increased over the past decade and medication administration is a skilled nursing function that requires the judgment of licensed nurses. Delegating this responsibility to medication aides increases the risk of medication errors, undermines resident safety, and enables nursing home operators to replace licensed nurses with lower-paid staff. Now is not the time to implement a statewide test; nor is it appropriate to allow this test to go on for 10 years.

New York nursing homes rank 43rd on total nurse staffing (3.62 hours per resident per day-HPRD), and 9th for the highest usage of contract staffing (10.8%) in the United States.¹⁰ When taking resident acuity into account however, nursing homes in New York should be at 5.06 HPRD.¹¹ Looking more closely at the data, of the nursing homes that submitted payroll based data (PBJ) to CMS for Q2 2025:

- 45.69% of nursing homes failed to meet the State minimum total (RN/LPN/CNA) staffing requirement of 3.50 HPRD. The average total HPRD was 3.71 with a range of 1.63 to 11.08. Taking into account expected total staffing based on acuity: the average total HPRD should be 5.04, with a range of 4.17 to 6.99. Only 9.95% of nursing homes met their expected total nurse staffing within 10%; 90.22% of nursing homes failed to meet their expected total nurse staffing based on acuity by 10% or more.
- The average RN HPRD is 0.71 with a range of 0.18 to 6.74. Taking into account expected RN staffing based on acuity: the average RN HPRD should be 1.03, with a range of 0.71 to 1.99.

⁹ See, for example, <https://ag.ny.gov/press-release/2023/attorney-general-james-sues-owners-and-operators-four-nursing-homes-financial> ; <https://www.syracuse.com/health/2025/01/van-duyns-shame-nursing-homes-out-of-town-owners-pocket-millions-while-residents-suffer.html>

¹⁰ <https://nursinghome411.org/data/staffing/staffing-q2-2025/>

¹¹ Harrington, C, McLaughlin, R, Saliba, D, Halifax, E, Mollot, R., Romano, P., Tancredi, D., and Mukamel, D., “Nursing Home Guide to Adjusting Nurse Staffing for Resident Case-Mix,” Journal of the American Geriatrics Society, May 2025. <https://doi.org/10.1111/jgs.19501>.

Only 16.47% of nursing homes met their expected RN staffing within 10%; 83.70% failed to meet their expected RN staffing by 10% or more.

- The average CNA HPRD is 2.22, with a range of 0.87 to 4.76. Taking into account expected CNA staffing based on acuity: the average CNA HPRD should be 3.28, with a range of 3.08 to 3.53. Only 5.15% of nursing homes met their expected CNA staffing within 10%; 94.85% failed to meet their expected CNA staffing by 10% or more. 55.93% met the State minimum staffing requirement of 2.2 HPRD.

Delegation does not solve staffing shortages. Operators, particularly certain for-profits, will do anything to reduce costs instead of staff based on resident acuity. For example, when the minimum nurse staffing levels came into effect, we saw nursing home operators in Western New York decrease the RN HPRD while increasing the LPN HPRD in order to meet the 1.1 RN + LPN minimum requirements. Resident quality of care and safety was directly adversely impacted.

Instead of increasing CNA and RN workload, the State should first ensure nursing home operators are meeting their federal and state legal obligations. As per the most recent determination by the Commissioner McDonald, for Quarters 3 and 4 of 2023, the majority of the State is not under an “Acute Labor Supply Shortage.”¹² When a nursing home is not meeting the State minimum nurse staffing requirements, DOH should automatically issue a citation for failure to meet the requirements and immediately open a complaint investigation for failure to maintain sufficient staff and other quality of care violations. The standards set forth by PHL 2895-b are already too low based on resident acuity. The State must do more.

There must be greater transparency to the public, including residents, their families and LTCOP, which nursing homes are failing to meet these minimum standards. Nursing home operators have the opportunity to appeal a cited deficiency, and request a redetermination of noncompliance and/or a penalty reduction application with the minimum staffing standards. Residents do not and are left to suffer the consequences: falls, bed sores, death.

The State can act by:

- Requiring DOH post the staffing levels of each nursing home and whether they are in compliance with PHL 2895-b on the nursing home profile website on the facility page;
- Include in the posting whether the nursing home has submitted a request for redetermination; and
- Provide copies of any request to redetermine compliance and/or penalty reduction application to the LTCOP, resident and family council.

¹² https://www.health.ny.gov/facilities/nursing/minimum_staffing/docs/commissioners_determination_2025-03-14.pdf

C. Reject Executive Budget Proposal HMM Part E to Repeal the Enhanced Quality of Adult Living Program

CELJ urges the Legislature to reject the Executive’s proposal to discontinue the Enhanced Quality of Adult Living (“QUAL”) program (SSL § 461-s).

The EQUAL program is a way to improve the quality of life for Adult Care Facility (ACF) residents who are in the greatest need. Specifically, the EQUAL program is a grant that is available to ACFs who provide housing and services to residents receiving SSI, State Supplemental Program (SSP) benefits, Safety Net assistance, and/or Medicaid (Assisted Living Program). Residents in these ACFs do not have access to the same quality services, food, activities, and environment, when compared to primarily private pay ACFs. Under this program, it is the residents who decide what the awarded funds should be used for including but not limited to: air conditioning in resident rooms, furniture, televisions, computers, transportation for resident services, and other activities and equipment. The residents make the decisions through their resident council.

The EQUAL program, when administered properly, improves resident quality of life, encourages resident participation in their daily lives and promotes autonomy.

For example: an ACF in the City of Buffalo was awarded EQUAL program funds and the residents decided to use those funds to purchase microwaves for resident use and upgrade the automatic doors in the building. In addition, they are starting to place computers on multiple floors for resident use. For the FY 2025-26 cycle, the residents are requesting a reserve of spare clothing for residents, room dividers for greater dignity and privacy, and upgrading activity items such as tables with games built in, pool and ping pong tables. As a result of resident involvement in the EQUAL program process, participation in resident council has substantially increased and more residents are engaged in using their voice and offering suggestions to the ACF.

Residents in other ACFs in Western New York have used the funds purchase air fryers (for resident use), one ACF created a movie theater for resident enjoyment, others invested in holiday decorations and enhancement of beauty/barber salons. Many used the funds for transportation to grocery stores or other outings.¹³

The EQUAL program strengthens residents’ connections to the broader community, promotes person-centered care, autonomy and meaningful choice for residents. It does not make fiscal or social sense to end the program. The Legislature must restore the EQUAL program.¹⁴

D. Support Investment in the Long Term Care Ombudsman Program

The Long Term Care Ombudsman Program (LTCOP) advocates for residents of nursing homes, adult care facilities and family type homes. Ombudsmen provide information and assistance to

¹³ To see what the residents have chosen to do with these essential funds, visit: https://www.health.ny.gov/facilities/adult_care/equal/

¹⁴ CELJ also opposes the Executive’s move to cut funding to the Coalition of Institutionalized Aged and Disabled (CIAD). While based in NYC and outside of CELJ’s geographic coverage area, CIAD is an essential watchdog that empowers residents and ensures access to legal and rights representation in adult home settings.

long-term care residents and their families in an effort to attain quality care. Ombudsmen are specifically trained to investigate complaints and resolve problems. As the chief advocate for residents who reside in nursing homes and adult care facilities, LTCOP plays a significant role in raising the level of care provided by these facilities and ensure each resident is treated with the dignity they deserve.¹⁵

Ombudsmen are meant to provide a “regular presence” in long-term care settings and because of this are able to get to know residents, their needs, and the things that make a difference in their everyday lives. Ombudsmen are another set of eyes. For those residents without any family or loved ones, ombudsmen may be their only socialization from outside the facility and the only advocate they can truly count on. The ombudsman becomes a “voice for the voiceless” and a lifeline for those who need assistance when they feel like they have nobody to turn to.

Recently, after decades of severe underfunding, the State has recognized the importance of ombudsmen and has increased funding to the LTCOP. Through increased investment, LTCOP has been able to make improvements. To ensure the continued increase in resident access to LTCOP, the State must increase its overall funding to \$10 million. Increased spending on LTCOP is associated with improved resident care in nursing homes.¹⁶

II. Support Home & Community Based Services and Implement Policies that Eliminate Institutionalization Bias

A. **Ensure Public Dollars Support Aging in Place in the Community, Not Private Business Interests**

Private Equity and for-profit business practices that siphon money away from direct care services must have no place in health care. The harms and adverse impact on patient care and increased costs have been widely reported.¹⁷ We have seen the direct harm of such practices in nursing homes. This misdirection of public funds to profits is also happening with home care and other health-related services. The State can and must do more to stop this practice in order to ensure every older adult has the ability to age in place in the community and the workforce is supported.

1. *Ensure Eligible Consumers Receive Home Care Services While Achieving Cost Savings*

CELJ supports A.2018A/S.2332A that would replace the failed Managed Long Term Care (MLTC) model with a managed fee-for service program that will ensure older adults have access to home and community-based services. A managed fee-for service model, whereby a care management entity would be paid to develop a care plan and authorize services, would ensure older adults and persons with disabilities who need long term services and supports actually receive said services.

¹⁵ For example, see: The Impact of Long-Term Care Ombudsman Presence on Nursing Home Survey Deficiencies Berish, Diane E. et al. Journal of the American Medical Directors Association, Volume 20, Issue 10, 1325 - 1330

¹⁶ Kennedy, K. A., Kosar, C., Williams, M. S., & Thomas, K. S. (2025). *Trends in Long-Term Care Ombudsman Program Funding and its Relationship to Nursing Home Resident Care*. The Milbank Quarterly, 103(4), 1029–1058. <https://doi.org/10.1111/1468-0009.70061>

¹⁷ KFF Health News. (n.d.). *Private equity*. <https://kffhealthnews.org/private-equity/> Accessed February 5, 2026.

After more than a decade it is clear; MLTCs have not delivered promised savings and have diverted billions of Medicaid dollars away from direct care. The Legislature must take action and pass A.2018A/S.2332A, a fiscally responsible alternative.

There are many reasons for the state to move in this direction:

- Plans are incentivized to deny care. Plans are paid the same per member per month premium for every member. This model was doomed to fail from the beginning because by definition, members are those with chronic conditions, aka high needs. MLTCs, in order to make a profit, deny needed home care and delay approvals for months.¹⁸
- Plans place barriers to members returning to the community after entering a nursing home for short-term rehabilitation/care. The carve-out of nursing home care from the MLTC benefit package, implemented in August 2020, exacerbates the incentive for MLTCs to limit access to high needs older adults. For example, we have seen MLTCs refuse to reinstate or increase home care for clients who needed the home care to return home.
- There is a lack of accountability and transparency. The State has failed to ensure that MLTC plans are properly following the law and model contract requirements. For example, in 2022, the NYS Comptroller found that the State paid \$2.8 billion in premiums to MLTC plans that provided little or no services, and another \$701 million for consumers who had died, moved to Assisted Living, or were otherwise not eligible for MLTC. CELJ, along with other consumer advocates, called on DOH to adopt long term care access standards recommended by CMS, and to post a publicly available quality dashboard with performance metrics such as the maximum wait time for home care services to be initiated after authorization.¹⁹

Replacing the failed MLTC model with managed fee-for service would help to ensure the State upholds its Olmstead obligations and would save billions of dollars that is currently being wasted with MLTCs. These savings can be invested in home care workers, who would generate a net economic gain of an estimated at least \$3.7 billion annually.²⁰

¹⁸ See *Mis-Managed Care: Fair Hearing Decisions on Medicaid Home Care Reductions by Managed Long Term Care Plans*, June-December 2015, by Medicaid Matters NY and NYS Chapter of National Academy of Elder Law Attorneys (July 2016), available at <https://medicaidmattersny.org/mltc-report/>. The report was featured in a story in the New York Times, Nina Bernstein, *Lives Upended by Disputed Cuts in Home-Health Care for Disabled Patients*, July 21, 2016, available at https://www.nytimes.com/2016/07/21/nyregion/insurance-groups-in-new-york-improperly-cut-home-care-hours.html?_r=0.

¹⁹ *Consumer Advocate Statement on New York State Comptroller Report of Aug. 5, 2022: Medicaid Program – Oversight of Managed Long Term Care Member Eligibility* (Nov. 2022, available at <https://medicaidmattersny.org/wp-content/uploads/2022/11/OSC-MLTC-report-consumer-advocates-statement-11.2.22-final.pdf>), citing CMS, *Promoting Access in Medicaid and CHIP Managed Care: Managed Long Term Services and Supports Access Monitoring Toolkit*, June 2022, available at <https://www.medicaid.gov/medicaid/managed-care/downloads/mltss-access-toolkit.pdf>.

²⁰ Jabola-Carolus, I., Luce, S., & Milkman, R. (2021). *The case for public investment in higher pay for New York State home care workers: Estimated costs and savings*. City University of New York, Graduate Center & School of Labor and Urban Studies. <https://slu.cuny.edu/wp-content/uploads/2021/03/The-Case-for-Public-Investment-in-Higher-Pay-for-New-York-State-H.pdf> The study came to its conclusion of at least 43.7 billion annually of net economic gain through reduced turnover, lower reliance on public assistance, increased tax revenue and broader economic spillover effects.

2. *Fair Pay for Home Care*

The State has an obligation to ensure older adults and persons with disabilities have access to the services and supports to live in the least restrictive setting; their community homes. Shortages within the home care workforce are a major contributing factor to older adults and persons with disabilities being unlawfully institutionalized. Low pay is a major contributing factor to the shortage. The State must invest in raising wages for home care workers, and can do so in part by ending the failed MLTC experiment.

In order to ensure nursing homes are the option of last resort (or actual individual choice), wage increase for the home care workforce must be made a priority. Without a healthy and financially sound workforce, there can be no home and community-based services and supports.

3. Protect the Consumer Directed Personal Assistance Program

As detailed in CELJ's written testimony²¹ before the Senate Standing Committees on Health and Investigations and Government Operations, and by the oral and written testimony of consumers, aides, and others²², the transition to a single Fiscal Intermediary (FI) has directly harmed older adults' ability to safely remain in the community.

For example we have a client who is a double hand amputee and a diabetic, who uses the CDPAP for his home care. For years he has been able to live independently in an apartment with the help of his PAs. He went through the PPL registration process with his PAs and thought they were properly registered. This was not the case. The result: the PAs stopped showing up as they were not being paid. Without their essential support, our client was unable to meet his care needs and the condition of his apartment deteriorated. His MLTC had to bring in a cleaning company, and the client private paid his PAs. The client faced an eviction proceeding due to the conditions of his apartment. The move to a single FI that has no state oversight or accountability directly impacted out client's health and housing stability.

Our client is not alone. CELJ urges the Legislature to include in the Budget the restoration of consumer choice by bringing back trusted, not-for-profit, FIs to end the PPL monopoly and require a public audit of PPL and establish permanent oversight to prevent future privatization disasters.

B. Repeal Harmful Medicaid Eligibility Changes to Preserve Community Living

The 2020–2021 State Budget amended the Social Services Law to impose new eligibility requirements for Personal Care Services (PCS) and CDPAP under MLTC. These changes went into effect on September 1, 2025, and require applicants to need assistance with physical maneuvering for three or more Activities of Daily Living (ADLs) to qualify, with a limited exception for individuals with Alzheimer's disease or dementia.

²¹ <https://www.elderjusticenyc.org/policy-testimony/cdpap-testimony>

²² <https://www.nysenate.gov/calendar/public-hearings/august-21-2025/joint-public-hearing-consumer-directed-personal-assistance>

CELJ supports S.358/A.1198 and urge the Legislature repeal this harmful change. Repeal is necessary to prevent continued and avoidable harm and preserve access to community-based care. The eligibility changes:

- Threaten the Ability of Older Adults to Age at Home

The new eligibility thresholds do not reflect how functional decline typically occurs. Many older adults require meaningful assistance to live safely at home but do not meet the heightened ADL requirement. Older adults who do not meet the 3-ADL threshold fall into a gap where their care needs exceed what aging services such as EISEP are able to provide. The result: individuals will be denied services until their needs escalate, increasing the likelihood of medical crises, hospitalization, or institutional placement.

- Increase Institutionalization and State Costs

When access to home care is restricted, individuals are more likely to enter nursing homes; often at higher cost to Medicaid than community-based care. Limiting eligibility for PCS and CDPAP undermines longstanding state and federal policy goals of providing care in the least restrictive, most cost-effective setting.

- Inconsistent with Federal Medicaid Policy

The amendments create distinctions among Medicaid consumers based on diagnosis rather than functional need. Federal Medicaid regulations prohibit arbitrary denial or reduction of required services based solely on diagnosis or condition. These changes place New York at risk of noncompliance with federal law.²³

- Raises ADA and Olmstead Concerns

By reducing access to community-based services and increasing the likelihood of unnecessary nursing home placement, the eligibility changes raise serious concerns under the Americans with Disabilities Act and the *Olmstead* integration mandate.

The 2020–2021 Budget also imposed a 30-month lookback period for Medicaid coverage of home care services. Although this provision has not yet been implemented, its impact, if allowed to take effect, would be devastating for older adults, people with disabilities and their family caregivers.

Under the lookback, individuals seeking Medicaid-funded home care would face lengthy delays before services could begin, even when the need for assistance is immediate and critical. Delays in home care do not merely create inconvenience; they create dangerous gaps in care that increase the risk of falls, hospitalization, caregiver burnout, and premature institutionalization.

Furthermore, this policy creates a stark and unjust double standard. When a Medicaid applicant enters a nursing home, care is provided immediately and Medicaid coverage, once approved, applies retroactively. In contrast, an individual who chooses to remain in their own home, at lower cost to the State, is left without essential services during the lookback period. The predictable result is that people are pushed into nursing homes simply to survive the waiting period.

²³ 42 C.F.R. §440.230(c): The Medicaid agency may not arbitrarily deny or reduce the amount, duration, or scope of a required service under §§440.210 and 440.220 to an otherwise eligible beneficiary solely because of the diagnosis, type of illness, or condition.

For family caregivers, the consequences will be severe. The lookback shifts the burden of care onto unpaid relatives, many of whom are older themselves, working, or managing their own health conditions. This strain accelerates caregiver exhaustion and increases the likelihood of institutional placement—precisely the outcome Medicaid home care is meant to prevent.

New York State failed to repeal the 3 ADL rule that is resulting in harm. The State must not make the same error and must pass A.1907/S.4786 to repeal the 30-month lookback. Repeal is essential to ensure that older adults are not penalized for choosing to remain in their homes and communities, and that Medicaid continues to function as a lifeline, not a barrier, to safe, dignified aging.

Thank you for the opportunity to submit this testimony. CELJ is available to answer any questions and provide additional information.

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Surviving on \$50 a Month: The Reality for Nursing Home Residents



CENTER FOR
ELDER
LAW &
JUSTICE

\$50 is the amount of money nursing home residents are allowed to keep of their income. This was set in 1988 and has not been increased since. In partnership with the NYS LTCOP, we launched a "Share Your Story" campaign and gathered more than 1,200 impact statements from nursing home residents, the results of which are reflected here.

Top Priority if Increased

40.5% of respondents stated

Clothing & Shoes



Inflation Adjustment

\$50/month in 1988 is equivalent to

\$140/mo

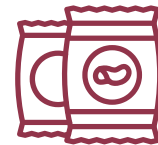
in 2026



How Residents Currently Spend \$50/month

27.7% of respondents stated

Snacks



In Their Own Words: \$50/month means...

- "I wear the same pants every day. I need shoes that fit, but I can't afford them."
- "I depend on donated clothing."
- "I have to choose between the shampoo that works for my skin and toothpaste, I can't buy both."
- "If I get my hair done, I can't afford to order food or go out at all that month."
- "I can't buy birthday or Christmas gifts anymore. That breaks my heart."
- "My phone bill takes most of the \$50. Without it, I'd be cut off from my family."
- "I worked my whole life. Living on \$50 a month is embarrassing."
- "I want to go shopping or out to lunch like a normal person, but I don't have the money."

Our Ask

Substantially increase the Personal Needs Allowance for nursing home residents with annual cost of living adjustments.

\$50 is not enough to cover even the most basic personal needs, especially as the cost of everyday items continues to rise. This growing gap between what residents are allowed to spend and what they truly need has tangible consequences for their quality of life, emotional well-being, and dignity. People living in nursing homes deserve more than mere survival. They deserve choice, compassion, and respect.

Contact Information

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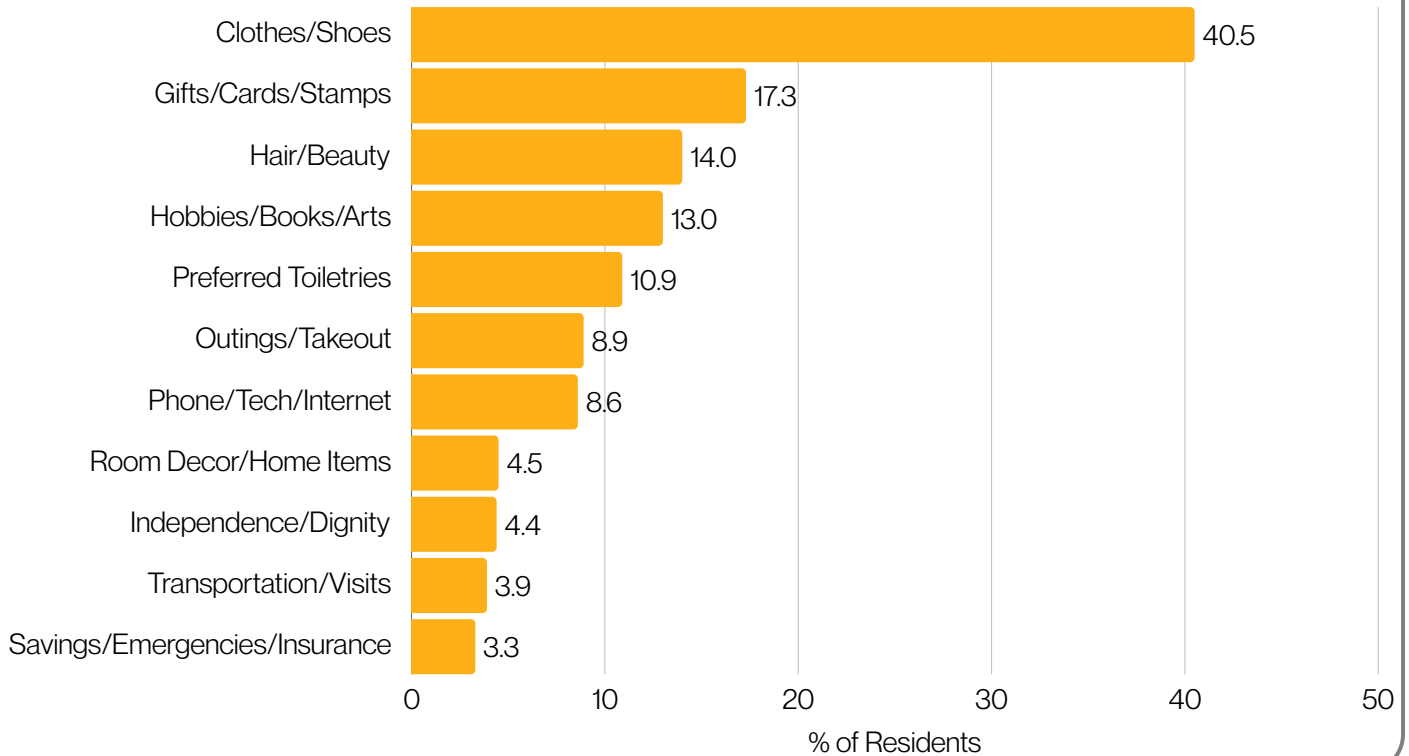
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Surviving on \$50 a Month: The Reality for Nursing Home Residents

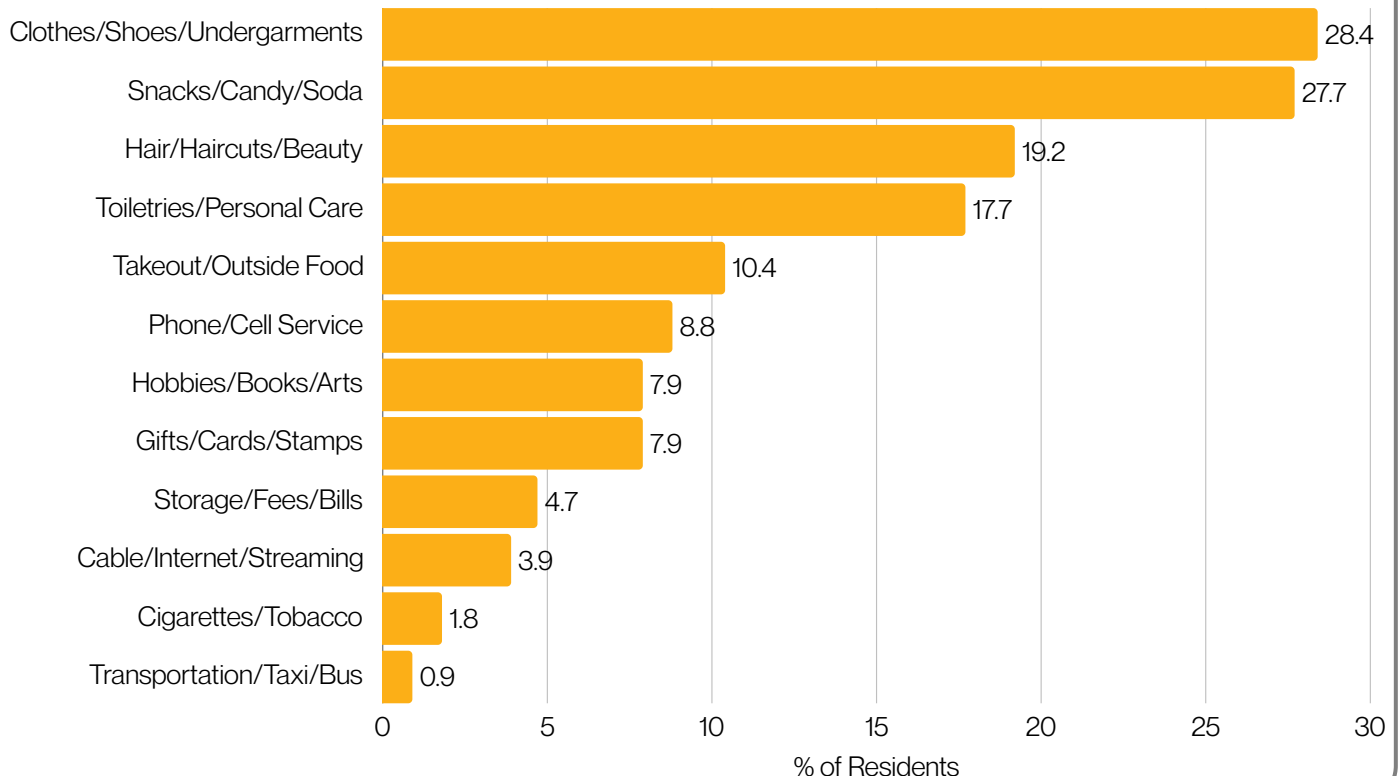


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Top Resident Needs/Priorities if Personal Needs Allowance is Increased



How Residents Currently Spend \$50/month



Summary of Responses from each regional Long Term Care Ombudsman Program

*The following are from the 'tell your story' campaign in partnership with the New York Office of the State Long Term Care Ombudsman whereby ombudsmen facilitated the survey/interview.

Region 1 (Suffolk):

165 Responses: Feel Human Again, get my nails done, offset costs of functional items (i.e.; portable wheelchair), make up, ordering Chinese or Pizza to eat with my friends, take a trip, specialty hygiene products, take a class to enrich my life, pay for my cell phone, to fix my motorized chair, not waiting as long to get my hair done, increase church dues, paying family back for purchases, more SCAT bus trips, family paying for cell phone and this is a burden to them. Sense of normalcy and dignity. More trips out of my facility and treating myself.

Region 2 (Nassau):

159 Responses: It would mean a lot to me to get more money." New clothes from losing weight, nothing fits. Electronic equipment, was always independent and is not, not wanting to be controlled. Vacation, uber/taxi ride to leave the facility, cigarettes, save money. Ability to buy adequate items. Allow me to buy beard kit monthly; magnifying glass; ABLE ride. Allow me to live with more comfort and not be stressed out, transportation. Because the food and coffee are so bad in nursing homes. I would be able to eat a little better and have a few more cups of coffee. I would not be going to bed hungry every night. We get a small (child size) pack of animal crackers 2x a week with coffee- what a delight it would be to have more often.

Region 3 (Bronx, Kings, New York, Queens, Richmond):

125 Responses: Buying in bulk would help me save money, cable tv, bottle or spring water. A new beginning. Ability to afford what I need. Allow me to purchase a sufficient amount of bulk items for several months without any interruptions or delay of receiving items I need for my family member. An increase in personal allowance for my mother would be a relief of financial burden making purchases on my mother's behalf. I would be able to replace her essentials more frequently and make purchases of better quality. Also, it would be money not deducted from my own family's budget. An increase would be great! We can pay for his private data service as well as other things we pay privately, hire someone to do his daily manicure which he needs. We can get him another newspaper subscription. He always has issues with his iPad so we can fix issues with an increase. Bottles Spring Water. I want to buy personal items for myself and for my family. My mother always buys everything for me, I want to be able to buy myself and get something for her.

Region 4 (Putnam, Rockland, Westchester):

46 Responses: Beta fish, fishbowl, pellets, dentures that fit me, travel out of facility for entertainment, would mean a lot of additional stuff, earphones, new sneakers, cosmetics, magazine subscription. I am a 57-year female and a resident here due to metastatic (terminal) breast cancer, spread to bones & liver. On the next page, I enumerate those items I need out because I cannot afford to purchase. More of what you need, I don't want to depend on others, order food -food in facility is awful; order groceries for self; pedicure in the community. religious organization; magazine subscription; books- my nursing home has no library. I get books from other residents.

Region 5 (Columbia, Dutchess, Greene, Orange, Sullivan, Ulster):

134 Responses: Visit a ranch or horse farm for day. Decorations for my room to make it feel like home. Winter coat, not so frugal about everything, visit my husband a little more. Donation to veterans' organization or St. Luke's Hosp. Cellphone, pay my bills, coat for winter. Decorations for my room to make it feel like home. Gift for my niece's birthday, new clothing. Family would not have to chip in any money for her hair apts. and personal items. Manicure, Hershey bars, candy, clothes, haircut, tape recorder to listen to music. More toiletries, insurance better plan, purchase a sweater or blouse. Will need furniture if you get a private room. Perfume, dusting powder, books, stamps, printer paper, shoes, plants, food/snacks.

Region 6 (Albany, Fulton, Hamilton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington):

82 Responses: I could buy some equipment to use with my computer like a better mouse, headphones so I can listen to podcasts and not have people ask me to turn the sound. It would make me feel like a human being again, not a caged animal. I could buy some new pillows. A lot of expense such as skin creams, socks, clothes, blankets, body wash, shampoo, snack foods, bananas, crossword puzzle books, word search books, are not covered under the current PNA allowance. Get my hair done once a month or more. Give donation to charitable organizations. Give my family and friends a small gift for their birthday and Christmas. Order out a few times a year. Buy cards for birthdays and Christmas. Buy books (I like to read). I would buy health insurance. I had a great husband family. My family is all on the other side of the country. I have only a few people in the area, a nephew and sister-in-law who don't like to come to nursing homes. I have lost my two younger brothers. I had a small business that got closed. I was able to give to charitable organizations, it makes me sad not to be able to do this anymore. I am not able to walk. I had a hip replacement in 2019 and my body is full of arthritis.

Region 7 (Clinton, Essex, Franklin):

61 Responses: Freedom to buy without worry less stress on me happiness and joy. I want to purchase CD and have more pay per view channels. Go to hairdresser more often, toothbrush, dental floss, Q tips, toothpaste, Maxi pads. I could buy clothes and be able to care for myself better. I could buy myself the products I like to use, and at least buy close family members gifts and cards. I could get a haircut and the things I need when I need them. I wish I could buy video games for something to do. I worked all my life, and all my money went to a nursing home. \$50 a month is embarrassing to have to live on. I can't even give someone a present. I would be able to buy a birthday card with \$3.00 in it. I would be able to buy small things that would make me feel wonderful. I definitely buy some soup and oyster crackers.

Region 8 (Jefferson, Lewis, St. Lawrence):

23 Responses: Able to put gas in sister's car for outings she takes me on, pay of back bills, better brand name stuff. Not worry about getting clothes and personal items. Able to purchase meals/takeout on occasion. Can get haircut, snacks, puzzles, and things i may need also pay my cable bill. He would like to go to the mall, go out to eat a few times a month. Would be able to get my hair done more frequently. Would be able to also get personal care products without having to ask others for the money. Would be able to provide the kids in my family with holiday gifts and cards. It would allow me to feel more independent. Would afford more funds available for special trips/outings, groceries such as treats, new clothing, etc. Very limited with current \$50. Would

like to have my hair done weekly, it would allow me to do that. It would allow me to go shopping for clothes. Would be able to get holiday and birthday gifts for my family.

Region 9 (Herkimer, Madison, Oneida, Otsego):

92 Responses: Fix my laptop that broke, get a new TV because mine is dying. I would be able to buy the brands that I want. I could buy myself books, fix my laptop that broke. I could get myself food I will eat since I don't like the food here. I could buy myself clothes that actually fit me. I need to get my hair done, but I have to save up for like 5 months to be able to afford it. Activities/outings to lunch or shopping could allow me to purchase items. Enjoying going out to eat more often, new clothing, glasses, other medical needs-cough drops, new shoes would be amazing. Everything! It would be like living like real people not like living poor. Everything!! No living month to month. Able to get things if there's an emergency. Example: My son is in the hospital & I can't get to him because I have no money. Growing up I lived in a great household, and I am used to having nice things. Can't happen on \$50 dollars a month.

Region 10 (Cayuga, Cortland, Onondaga, Oswego):

6 Responses: Art supplies, I could do more the way I use to be before I lived in a nursing home, a new phone, new clothes since I can afford now because I pay for cable, buy things I like without having to wait on staff to get it for her. Give me more back up and allow me to do more artwork during my own time. I can make gifts for my friends. It would help me pay for a better phone. I could buy more for my niece and nephew at holiday times. This would let me get things I would like without having to wait for staff to get it for me. I would like to buy things on the internet myself. I used to like shopping. I would be able to buy some new clothes. I would buy a pretty new blouse.

Region 11 (Broome, Chenango, Delaware, Tioga):

12 Responses: Could get a radio for my room, nail polish is a luxury. Could get a radio for my room. \$10 - phone, \$10 - TV, facility takes out and have my hair cut. If I had more, I would buy name brand personal product, nice soap. "It makes you feel more like a person. New glasses. Nail polish is a luxury. Due to the high cost of living and the increased inflation (especially during these past few years) the bump up to 200 dollars a month would be very welcome! I purchase my own shampoo, body wash, moisturizing lotions - products my are used to. I use the same body mist I've used for years - Cherry Blossoms. I create drawings/colorings in my spare time and the supplies I need are paper. sketch pads, colored pencils, gel pens, templates, etc. I crochet in my spare time, scarves, shawls, Afghans, and I need supplies for everything I make. I have a collection of books of word puzzles, which I'm always renewing. I have a supply of spiritual guidance book. favorite music, favorite old movies. My computer is covered for the \$20/month. A new sweater a year - \$40. A new nightgown a year - \$20. A pair of slippers - \$15. A new supply of holiday cards - \$20. Snacks for my cupboard; popcorn, Cheez its, Reese's cups, etc. - \$25. Out in "the real world" everything costs something and anything in a nursing home, the basics are covered, but the interactive daily existence costs much more than \$50/month.

Region 12 (Chemung, Schuyler, Tompkins):

36 Responses: Buy a DVD player and some movies, I could buy leisure items not necessities, cover unexpected expenses. A great deal. I would be able to buy things I need. A gift for my mother. Clothes - slippers, winter clothes, blue jeans lost in laundry hair cut eat in restaurant

participate in field trips and attend performances that cost money simple track phone and small room fan. Ice cream & soda, snacks, haircut, socks. I'd have more money to take on a new hobby. It would help to cover unexpected expenses. More money so I can buy small gifts to the staff to show them how much I appreciate them. New Clothes. New Glasses. New Shoes and Socks. She wouldn't have to scrape by with her money and then she'd have extra. That I wouldn't have to constantly have to ask my family for more money. Watch more movies.

Region 13 (Genesee, Livingston, Monroe, Ontario, Orleans, Seneca, Wayne, Wyoming, Yates): 66 Responses: It would mean being able to buy many more art supplies to draw and paint not just me but me and friends. Book clubbing, it would lift my spirits so that I would feel more independent instead of asking family so many times thereby giving me a not so "poor" feeling. Happiness, able to live comfortably. I would buy Christmas cards and birthday cards and decorate my room. I would be able to buy some things for my family for helping me out. Could buy some snacks to eat during the day. Clothes for myself, pants. New shoes, slippers to keep my feet warm. More electronics, more toiletries, food, peace of mind, gifts for daughters, clothes. Wegmans, Field trips, Personal toiletries. That would help a lot!! She would use the money to get her hair done. Buy more clothes, food. Would like to buy soda, juice. Needs new underwear. Would buy gifts for family at holiday time.

Region 14 (Allegany, Steuben):

20 Responses: I wouldn't have to wait months at a time for it to happen. Allows me to purchase my personal needs, reading mat. Snacks without having to budget. I wouldn't have to wait months at a time for it to happen. Hopes that people realizes that those in a nursing home can live as closely/comfortable as those not in one. The prices are much different than they used to. \$50 is like nothing. Remember the one that are forgotten (nursing home residents). Would be nice to know I have it in case I need it. Would sure love to have a bit more to spend. Thank you for thinking of us. More personals and I have found out that women can never have enough personals for my life. I do not have family to take care of me. I don't give away the stuff I receive from the bingo store, and I get full and I don't know what to do anymore. Thank you so much for caring. I would be able to get my preferred body wash/lotion, a scrub for myself. I would be able to get stuff for my hair. I would be able to get everything I need and treat myself like I used too.

Region 15 (Cattaraugus, Chautauqua, Erie, Niagara):

107 Responses: Repay my family that has been buying me things, I would be able to buy clothes from this century and not have to wear any 197-s t-shirts. It would mean that I wouldn't have to rely on family to support me during the months that I don't have enough cash flow to support me. It would mean not having to worry as much, as to what to buy or not go buy. It would help me get more stuff. Times are hard. \$50 can't get nothing. Everything is expensive. It would allow me to go out with my sister & buy clothes, perfume, hair products, music. It means I can purchase more things like clothing, snacks, books, shoes, slippers, and haircuts. I'd order out more often. I'd like to be able to give my sister money to buy me shampoo and grease for my hair. Also, I'd like to get personal hygiene things. I'd buy more cigarettes, personal care things - deodorant, cologne. I'd also send gifts to my family.