

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

#### 2025-2026 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 2025-2026 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.<sup>1</sup> 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 seeks in part to improve the health and well-being of every New Yorker, increase affordability and access to quality health care, and places emphasis on "putting money back in New Yorkers' Pockets. The proposed Budget does include an additional \$45 million for non-medical in-home services provided through the State Office for the Aging. However, overall, the proposed Budget fails to intentionally include a valuable part of our community, older adults. While the proposed Budget does not include deep cuts to Medicaid and eligibility that we have seen in prior years, the proposed Budget fails to invest in and support the right of older New Yorkers to age in place and with dignity.

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

<sup>&</sup>lt;sup>1</sup>Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Livingston, Niagara, Orleans, Steuben, and Wyoming Counties

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A. Increase Personal Needs Allowance for Nursing Home Residents

**CELJ urges the Legislature and the Executive to increase the Personal Needs Allowance** ("PNA") from \$50 to \$200 with provisions for annual increases based on the consumer price index. The PNA has not increased since the 1980s and does not take into account inflation. The PNA is the monthly sum of money that nursing home residents who receive Medicaid (the majority of long-term care residents) are allowed to retain from their Social Security benefit and other sources of income, to spend on personal items and services that are not provided by the nursing home. The balance of their income, the Net Available Monthly Income ("NAMI") goes towards to the cost of their care.

Billions are being proposed in inflation rebates and middle-class tax cuts, along with increases for health care providers. Persons who live in nursing homes must not be abandoned to live on a paltry \$50 a month (\$600 a year).

The Medicaid nursing home benefit only covers nursing services, dietary services, certain activity programs, room/bed, routine personal hygiene items and medically related social services.

Medicaid does not pay for essential personal items and miscellaneous expenses that occur in a resident's day-to-day life. Such items include a haircut, clothing and shoes, a card for a grandchild, quality toiletries, favorite foods or snacks, streaming services, TV, internet, a phone, non-medical transportation, and more. The PNA, currently set at \$50 (income other than SSI) and \$55 (SSI \$30 + \$25 from the State, for those eligible), denies residents the access to and enjoyment of items that are part of everyday life. This has an adverse impact on resident dignity and health.

In 2021-2022 New York State enacted a variety of reforms aimed at addressing home resident rights and safety standards: minimum nurse staffing standards, involuntary discharge/transfer protections, minimum direct care spending requirements and others. These reforms focused on the actions of operators/providers and their responsibility to improve and promote resident rights, health and safety. The reforms did not directly address resident quality of life, as determined by the residents, which an increase in the PNA will achieve.

The proposed Budget and prior budgets have increased funding to nursing home operators but failed to allow for residents to retain more of their own income. For example, the proposed Budget provides for the annual pass-through of federal SSI cost of living adjustment so that persons who live in Enhanced Residential Care and other settings see an increase in their PNA.<sup>2</sup> Yet, the State has never increased the PNA for nursing home residents for cost-of-living adjustments.

In 2024, CELJ partnered the New York Office of the State Long Term Care Ombudsman, and conducted a survey of current and former residents, their families, and their supporters, to directly hear from them the impact of the current PNA amount. The survey had two questions: what does the \$50 PNA allow you to purchase for yourself or loved ones, and what would an increase in the PNA mean to you? The survey resulted in over 1,200 impact statements being collected throughout the state. The responses were heartbreaking and included:

- I would be able to live like a human being.
- At \$50 I am being abused-emotionally! I would be able to buy a birthday card with \$5 in it.
- I would be able to buy newer clothes. I'm wearing the same clothes for the past 7 years.
- I won't be able to maintain cellphone service if not increased.
- [With an increase] I'd be allowed to see my family and friends, now I have to rely on others.

We also received responses from nursing home staff. For example, a Director of Financial Reimbursement, who worked in the finance office for 19 years, responded: "it is unjust a resident is only allowed to keep \$50 per month and has not changed for 34+ years especially with high inflation... [an increase] would help everyone! [It] would help the residents so they feel they are no bother to those they love. It's upsetting when you worked hard all your life and you want to regain your independency."<sup>3</sup>

New York has the authority to increase the PNA but has not done so since the 1980s. The PNA was intended to provide residents with an effective dollar amount each month to pay for a variety

<sup>&</sup>lt;sup>2</sup> Proposed budget EFLA Part R

<sup>&</sup>lt;sup>3</sup> A summary of survey responses broken down by LTCOP region, as known is <u>enclosed</u>. All respondents to the survey did not include their part of the state.

of expenses in their day-to-day life that are not included in what their NAMI and Medicaid pays to the nursing home for their care. <u>\$50 simply does not go far enough and in fact degrades resident</u> dignity, independence, and quality of life. This is a human rights issue.

A.2048 would increase the personal needs allowance to \$200 and require an annual adjustment reflecting the latest consumer price index and must be included in the final Budget. The proposed Budget seeks to bring affordability to all New Yorkers. Persons who live in nursing homes must be included. The increase per person is minimal compared to the entire proposed Budget, which includes millions of additional funds to nursing home operators:

- Residents who are on chronic care Medicaid with a NAMI: additional \$1,800 per resident per year. (A total of \$2,400 they get to retain from their income.)
- Residents whose income is SSI and eligible for the state payment: additional \$1,740 per resident per year. (Brings residents who are on SSI and eligible for the state payment to the \$2,400 a year total.)

Persons who live in nursing homes deserve to live with dignity and pride, not to be forced to live destitute, cut off from the community, and without the ability to purchase basic life necessities. The abhorrently low PNA compromises the human rights and basic needs of residents.

B. Reject Executive Budget Proposal HMH Part V subpart A 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.<sup>4</sup> As referenced above, in 2021-2022 New York State enacted a variety of reforms to address long-standing failures and improve the quality of care for all residents. While enforcement of these reforms must be strengthened, these reforms are being attacked through litigation and legislation, with a goal to weaken or repeal. <u>CELJ urges the Legislature and the Executive to reject actions that will weaken these essential laws</u>.

Specifically, CELJ urges the Legislature to reject the Executive's proposal to authorize certified medication aides to administer medications in nursing homes.<sup>5</sup> While promoted by supporters as a no-cost strategy address staffing concerns, if implemented, the quality of care will decline, and resident safety will be adversely impacted.

Nursing home operators are required under federal and state law to ensure resident care needs are met based on the individual's plan of care, this includes medication administration and management from licensed nursing staff. Resident acuity has increased over the past decade, and

<sup>&</sup>lt;sup>4</sup> See, for example, <u>https://ag.ny.gov/press-release/2023/attorney-general-james-sues-owners-and-operators-four-nursing-homes-financial</u>; <u>https://www.syracuse.com/health/2025/01/van-duyns-shame-nursing-homes-out-of-town-owners-pocket-millions-while-residents-suffer.html</u>

<sup>&</sup>lt;sup>5</sup> CELJ also opposes A1272. One of the reasons used to support the bill is NY's OPWDD system uses direct support professionals (DSPs) to administer medications, typically the medical care needs of that population are less complex than persons who reside in nursing homes. In addition, there is no publicly available data or other research that demonstrates the efficacy and safety of DSPs administering medications.

persons living in nursing homes are more medically and socially complex. Instead of increasing CNA and RN workload, the State should first ensure nursing home operators are meeting their federal and state legal obligations. The State can start by ensuring nursing home operators are meeting the minimum nurse staffing standards set forth under Public Health Law 2895-b.

Longstanding research has shown that higher RN staffing increases quality outcomes.<sup>6</sup> Yet, there is limited research on the issue of medication assistants in nursing homes, and that research has mixed results. For example, one study evaluated the impact of the use of medication assistants in a rural eastern Washington State nursing home. It found that while the number of LPNs scheduled to administer medications slowly declined, as the number of medication assistants increased, the number of inspection deficiencies more than doubled from 2017 to 2019.<sup>7</sup> Another study, from 2013, found mixed results regarding the potential benefits/harms of having CNAs distribute medication. Specifically, it found that where nursing homes reduced RN/LPN staffing levels, and used medication aides, there were increases in the numbers of residents who needed help with ADLs, who lost continence, and who were depressed/anxious.<sup>8</sup>

NYS ranks 29<sup>th</sup> in direct RN staffing, 45<sup>th</sup> in total nurse staffing, and 9<sup>th</sup> for the highest usage of contract staffing (12.2%) in the United States.<sup>9</sup> The State must place greater efforts and emphasis on ensuring each nursing home operator is meeting federal and state requirements on RN and other direct nurse staffing before adding any additional burdens on already overworked RNs and CNAs.

CELJ further opposes A.600 and other efforts to further dilute the minimum nurse staffing standards in nursing homes. While it is important that nursing homes have physical, occupational, and recreational therapists and assistants, these, along with any other proposed staff minimum standards, must be in addition to the minimums set forth under Public Health Law 2895-b.

DOH has the oversight and enforcement authority to ensure nursing home operators are properly utilizing private and public funds on resident care and the State can do more to hold bad actors accountable. For example, Public Health Law 2803-x requires nursing home operators:

- Disclose common or familial ownership of any corporation, other entity or individual providing services to the operator or the facility;
- Notify DOH and LTCOP prior to executing a letter of intent or other contractual agreement related to the sale, mortgaging, encumbrance, or other disposition of the real property of the facility and the consulting, operations, staffing agency or other entity to be involved in the operations of the facility.
- Notify residents and their representatives, staff and their representatives and LTCOP within 5 days of executing such agreements.

<sup>&</sup>lt;sup>6</sup> See Harrington C, Schnelle JF, McGregor M, Simmons SF. The Need for Higher Minimum Staffing Standards in U.S. Nursing Homes. *Health Serv Insights*. 2016;9:13–19. Published 2016 Apr 12. doi:10.4137/HSI.S38994 – that documented over 150 staffing studies have been done, and that the strongest positive relationships are found between RNs and quality, and that total nurse staffing is directly related to quality.

 <sup>&</sup>lt;sup>7</sup> Crogan NL, Simha A.. Impact of Medication Use on Nursing Home Staffing Levels and Inspection Results. Gerontology & Geriatrics. Sept 17, 2020; <u>https://austinpublishinggroup.com/gerontology/fulltext/ggr-v6-id1044.pdf</u>
<sup>8</sup> Walsh JE, Lane SJ, Troyer JL. Impact of medication aide use on skilled nursing facility quality. Gerontologist. 2014 Dec;54(6):976-88. doi: 10.1093/geront/gnt085. Epub 2013 Aug 22. PMID: 23969257

<sup>&</sup>lt;sup>9</sup> Q2, 2024 <u>https://data.cms.gov/quality-of-care/payroll-based-journal-daily-nurse-staffing</u>

These disclosure requirements, along with operator submitted costs reports, provide the DOH with the necessary information to fully review and assess how funds are being spent (and potentially misspent) and cross reference to staffing levels and quality of care.

New York must implement a budget that addresses resident care and safety and holds operators accountable. As most recently reported on by the Syracuse Post,<sup>10</sup> residents should not be forced to reside in horrific conditions. New York has an obligation to ensure older adults and persons with disabilities can age in place and remain in the community. New Yorkers of all ages and abilities want to, and deserve to, thrive and live with community<sup>11</sup>.

# C. Reject Executive Budget Proposal HMH Part H 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 ("EQUAL") 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. We provide two examples through our partnership with the NYS Region 15 LTCOP:

- 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. 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.
- Two ACFs in Chautauqua County that are operated by a non-for-profit, where over half the residents in one ACF are recipients of SSI or have a decreased monthly fee due to income and asset level, and the other ACF has over 85% of residents who low income and recipients of SSI. Residents in both ACFs have benefited from the EQUAL program. In working with the

<sup>&</sup>lt;sup>10</sup> <u>https://www.syracuse.com/opinion/2025/02/van-duyn-residents-have-suffered-enough-ny-needs-to-crack-down-editorial-board-opinion.html</u>

<sup>&</sup>lt;sup>11</sup> As CELJ wrote in its 2021 budget hearing testimony, if it is inappropriate for people with developmental and intellectual disabilities to be in institutions, why is it ok for our older adults and other people with disabilities? See Timeline from the Museum of Disability History <u>https://www.museumofdisability.org/virtual-museum/new-york-wing/new-york-state-timeline-exhibit/</u> see also <u>https://disabilityjustice.org/reform-and-closing-of-institutions/</u>

residents, EQUAL program funds were used to support resident quality of life improvements including:

- Updating common space furniture and 20-year-old wall covering;
- Conversion of a space from an unused nook to a kitchen area where residents can cook if they choose;
- Provide shopping trips at no cost to the residents by offsetting transportation costs;
- Install awnings to promote outdoor activities; and
- Install sidewalks for safe mobility and connection to the surrounding community.

The EQUAL program helps residents age in place with independence, autonomy, dignity, and remain connected with the community.

#### 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 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 long-term care residents in both nursing homes and adult care facilities, LTCOP can play a significant role in raising the level of care provided by these facilities and ensure each resident is treated with the dignity they deserve.<sup>12</sup>

Ombudsmen are meant to provide a "regular presence" in facilities 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 in facilities. 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 LTCP. Last budget, LTCOP received \$3.69 million with an additional \$2.5 million from the legislature. Through the increased investment, LTCOP has been able to make improvements. For example, between 2023 and 2024:

- Facilities receiving weekly coverage, or regular presence increase from 12% to 18%.
- Total staff in regional programs increase by 21% with FTE's increasing by 20%.
- Total number of overall facility visits increased by 31%.
- 94% of all facilities received at least one visit during 2024, an increase of 9%.
- Facilities receiving routine access, or one visit in each quarter of the year increased from 53% to 81%.
- Complaints received by the ombudsman program showed a significant increase of 60%.<sup>13</sup>

 <sup>&</sup>lt;sup>12</sup> 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
<sup>13</sup> Information obtained from the New York Office of the State Long Term Care Ombudsman.

The proposed Budget has level funded the program at \$6.19 million. This is positive and because of the recent increase, more residents have access to LTCOP. To ensure the continued increase in resident access to LTCOP, the State must increase its overall funding to \$10 million.

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

## A. Repeal Harmful Changes to the Medicaid Program that Promote Institutionalization

The 2020-2021 Budget amended the Social Services Law to set new minimum requirements for eligibility for PCS and CDPAP services for eligibility to enroll in a Medicaid MLTC plan. Under these enactments, applicants have to require assistance with physical maneuvering for 3 ("more than two"), Activities of Daily Living, except for applicants with dementia or Alzheimer's. For applicants with dementia or Alzheimer's, only supervision with more than one ADL is needed.

These amendments create irrational and discriminatory distinctions between Medicaid consumers with different types of disabilities. These irrational and discriminatory distinctions are arbitrary and violate federal regulation.<sup>14</sup> Furthermore, these amendments will force older adults and people with disabilities inappropriately into nursing homes. This outright violates the Americans with Disabilities Act and the Olmstead integration mandate.

Thankfully these changes have not yet been implemented. We urge the legislature to act now to avoid unnecessary harm to older adults. <u>CELJ supports S.358(Rivera)/A.1198(Paulin) and urge the Legislature and the Executive to repeal this harmful change.</u>

In addition, the 2020-2021 Budget set forth Medicaid cuts to access to home care services through a 30-month lookback. While also not yet implemented, if implemented, would delay receipt of Medicaid covered home care services for older adults and persons with disabilities, and will cause unjust institutionalization and further strain on familial caregivers. When a Medicaid applicant is in a nursing home, they are receiving care and services. Medicaid, if approved, will cover the care retroactively. However, when a Medicaid applicant is in the community, a lookback will delay the approval process leaving the individual without essential home care services that are needed for the individual to remain in their home. <u>CELJ supports A.1907(Paulin) and urges the Legislature and the Executive to repeal this harmful change</u>.

## B. Eliminate Resource Test for non-MAGI Population

The 2022-23 Executive Budget expanded Medicaid eligibility of older adults and persons with disabilities (Age, Blind, Disabled- "non-MAGI"), by raising the income eligibility from 84% of the Federal Poverty Level to 138%, aligning it with the MAGI population. Unfortunately, the Executive's proposal that year to repeal the Medicaid asset test for non-MAGI was not included in the final budget. We again urge the Legislature to eliminate the asset test for the Non-MAGI

<sup>&</sup>lt;sup>14</sup> 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.

population. It is discriminatory and furthers the racial divide in equitable health care access as individuals covered under MAGI Medicaid are not subject to an asset test.

In the alternative, short of a full repeal, the State can make access to health care more equitable by increasing the liquid asset limit. For example, California eliminated the asset test following a two-phased approach: 2022, increased the asset limit to \$130,000, then in 2024 eliminated the asset test. The State can start this approach by passing A.1043/S.3554 to raise the asset limit, then eliminate it thereafter.

## C. Protect the Consumer Directed Personal Assistance Program

CELJ supports the statements and information presented by NYLAG in its written testimony and urges the Legislature to repeal and replace the transition to a single fiscal intermediary ("FI") for CDPAP. S.1189/A.2735 sets forth a process for the selecting and licensing of fiscal intermediaries which includes a character and competency review and a determination by DOH whether the FI and their services are fit and adequate. This legislation would also authorize the Comptroller to review contracts entered into by the FI and provides the Comptroller with the authority to refer FIs that are engaged in unlawful activity to the Medicaid Fraud Control Unit and DOH.

## D. Fair Pay for Home Care

The State has an obligation to ensure older adults and persons with disabilities are provided with 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.

The State must realign such that nursing homes are the option of last resort (or actual individual choice), and not the first. This cannot be achieved until the State's home care delivery system is stabilized and reliable.<sup>15</sup>

Wages for persons who provide home care services to older adults and persons with disabilities must be made a priority. Without a healthy and financially sound workforce, there can be no home and community-based services and supports. This investment is needed to support older adults and persons with disabilities to age (and work) with independence, autonomy, and dignity

## E. Ensure Eligible Consumers Receive Home Care Services While Achieving Cost Savings

CELJ supports A.2018 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

<sup>&</sup>lt;sup>15</sup> See Sterling et al. "Utilization, Contributions, and Perceptions of Paid Home Care Workers among Households in New York State." Accessed https://academic.oup.com/innovateage/advance-

article/doi/10.1093/geroni/igac001/6499014?login=false, See also: Jacobal-Carolus, Luce, Stephane, Milkman,

Ruth. "The Case for Public Investment in Higher Pay for New York State Home Care Workers-Estimated Costs and Savings-Executive Summary., Accessed

https://static1.squarespace.com/static/58fa6c032e69cfe88ec0e99f/t/6022ae8312cfd1015354dbee/1612885635936/Ex ecutive+Summary+CUNY+REPORT.pdf

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.

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.<sup>16</sup>
- 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 the 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.<sup>17</sup>

Replacing the failed MLTC model with managed fee-for service would help to ensure the State upholds its Olmstead obligations and would save the State millions in dollars that is currently being wasted with MLTC.

III. Support Enhanced Consumer Protections from Medical Debt

## A. Support: Executive Proposal HMH Part L – Update Medical Debt Consolidation

CELJ supports the proposal to amend Public Health Law 18-C to require that consent to pay for healthcare services be obtained prior to the receipt of the service by the patient. This provision will

<sup>&</sup>lt;sup>16</sup> 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 <u>https://medicaidmattersny.org/mltc-report/</u>. 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 <u>https://www.nytimes.com/2016/07/21/nyregion/insurance-groups-in-new-york-improperly-cut-home-care-hours.html? r=0.</u>

<sup>&</sup>lt;sup>17</sup> 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-<u>11.2.22-final.pdf</u>, 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.

empower individuals requiring non-emergency care to make informed decisions about whether and when to undertake medical services that can potentially devastate their financial lives. Medical care can be outrageously costly, especially when insurance coverage is incomplete or unavailable. If individuals have information up front on the costs that will be associated with their care, they will have greater ability to control their medical expenses and can budget for these expenses as opposed to facing expenses they were not prepared to incur.

For instance, one of CELJ's clients had been given misinformation that her insurance would cover a non-emergency medical procedure that was not urgently needed. Even though she was given information up front about costs, this information was wrong so her situation was akin to having no notice of the costs she would incur. She consented to receive care on the basis of misinformation. Five months later, the client was informed that this information was incorrect and there was no coverage available. This individual could not pay the bill and was ultimately sued on it, adding thousands of dollars to her costs in the form of attorney's fees. Had she had reliable information and counseling upfront, she would have delayed the procedure until she was financially able to afford it.

Another of CELJ's clients was given the option up front to decide on purchasing medication that was prescribed. This individual declined to consent to receiving the medication because the monthly cost, even after insurance coverage was applied, was more than his monthly income. The individual was sent the medication despite declining but was able to receive a refund, avoiding a potentially disastrous consequence of being liable for an expense that he would never have been able to pay.

This proposal will be especially beneficial if accompanied by requirements that patients be counseled on their insurance benefits as well as their rights to apply for charity care or other financial assistance as part of the consultation regarding consent to payment. CELJ continues to see many clients being sued for medical debts that were not aware of their right to apply for financial assistance.

## B. Support: Stop SUNY Suing for Medical Debt

CELJ supports A.1356/S.359 and advocates for its inclusion as part of the final 2025-2026 Budget. The legislation would prohibit the five state-operated hospitals<sup>18</sup> from suing patients for medical debts. These hospitals receive a disproportionately larger share of the federal and state funds that allow hospitals to provide charity care. In addition, a recent report by the Community Service Society of New York revealed that these five hospitals were responsible for 80% of the state's medical debt lawsuits in 2023. Many of these suits are filed against individuals who should qualify for charity care.<sup>19</sup>

## C. Support: Consumer and Small Business Protection Act

<sup>19</sup> Mia Wagner, Marielle Ray, Elisabeth Ryden Benjamin. "Discharged Into Debt: State-Run Hospitals Filed Over 80% of Medical Debt Lawsuits in New York in 2023.", available at:

<sup>&</sup>lt;sup>18</sup> SUNY Upstate, SUNY Downstate, SUNY Stonybrook, Roswell Park, Helen Hayes Hospital.

https://www.cssny.org/publications/entry/discharged-into-debt-state-run-hospitals-lawsuits-stop-sunysuing?org=1900&lvl=100&ite=1499&lea=257039&ctr=0&par=1&trk=a2APc000000hROLMA2

CELJ supports S105, the Consumer and Small Business Protection Act, and advocates for its inclusion as part of the final 2025-2026 Budget. This legislation updates New York's woefully outdated business law and would ban unfair, deceptive or abusive acts or practices in the conduct of business, trade or commerce or services, and affords consumers who have been harmed greater judicial remedy.

While not limited to medical debt, or actions by health care providers, this legislation is needed to ensure nursing home residents, and their family/friends are not unlawfully and unjustly taken advantage of. For example, a nursing home sued a stepdaughter for her stepmother's unpaid bill. The stepdaughter signed an admission agreement as "Responsible Party" that held her personally liable if the resident failed to pay. The nursing home would not admit her stepmother unless her stepdaughter signed. At the time when she sought admission the stepmother was very ill and there was no other place for her to go where she would be able to get the care she needed. This is in direct contradiction to the federal Nursing Home Reform Act stating that a nursing home may not include provisions asking Responsible Parties or other third parties to take no personal responsibility for payment of another's bill. Another client is being sued for a nursing home debt for a rehab stay when the facility failed to submit the bill to her insurance for coverage under Medicare Part A. The facility instead decided to charge her the private rate of pay for room and board and other charges, and then sued her before the bill was ever submitted, and while she has a pending application for Medicaid that may also help to cover the bill.

#### IV. Invest in Civil Legal Services

CELJ, as a civil legal services agency, is part of the social safety net in New York State. Our services address unmet social needs, living environments, and barriers to accessing health care. These factors, known as social determinants of health ("SDOH"), have direct impact on an individual's ability to age in place with dignity and independence. Access to civil legal services is one of the key factors to addressing SDOH and support older adults to remain a part of the community.

Unfortunately, however, lawyers and other staff are leaving legal services agencies for government jobs at an alarming rate because civil legal services organizations statewide are unable to achieve pay parity with those attorney counterparts working in government positions, such as the New York State Attorney General's Office. The combination of higher salaries and a government pension is difficult to compete against, particularly for mid-career attorneys.

Pay for attorneys in civil legal services is significantly lower than their government counterparts doing substantially similar work, with civil legal services outside of NYC getting paid **21%** less than their counterparts in the Attorney General's office. Those inequities only grow throughout their careers and, after 21 years of civil legal services employment, experienced civil legal services attorneys are paid **38% less** than their counterparts in the AG's office in some parts of the state, based on a 2024 survey of Legal Services Coalition members.<sup>20</sup>

It is acknowledged that New York State cannot single-handedly fix the justice gap overnight, but it is also abundantly clear that the gap will widen without both a direct investment from New York State in civil legal services, and the preservation of one of its core funders, the IOLA Fund.

<sup>&</sup>lt;sup>20</sup> www.nylscoalition.org

The Interest on Lawyer Account Fund of the State of New York ("IOLA") currently provides funding to eighty-one different providers of civil legal services to low-income New Yorkers. IOLA's 2024 annual report shows an estimated economic impact of around **\$5.32 billion** from its Fiscal Year 2024 and 2025 grants totaling **\$750 million**, including **\$1.95 billion** in direct benefits to clients and families, and around **\$844 million** in cost savings to the community (for avoidance of emergency shelter and domestic-violence-related costs).<sup>21</sup>

Thankfully, the SFY 2026 Executive Budget provides the necessary funding for the first of fiveyear IOLA contracts that are providing increases to providers. The budget also correctly recognizes IOLA as a fiduciary fund. However, missing from the Executive Budget is 2.5 million that IOLA requested for their Infrastructure Project, a historic investment in its grantees, which will improve the consistency, efficiency, and coordination of the legal services delivery system. We urge full funding of the IOLA request of **eighty million** dollars.

In addition, the Judiciary Budget includes a \$45.5 million increase for Judiciary Civil legal Services. The community is grateful for this significant investment in access to justice and we know that the Chief Judge and his staff understand the difficulties facing low-income litigants in New York State. In the OCA budget, the funding is designated as such:

- "The funding supports a 3% cost-of-living adjustment and necessary additional funding to address critical needs for the poorest New Yorkers.
- An increase of "\$45.5 million including \$23.1 million base and \$22.4 million enhanced funding."

Pay parity is a critical issue from an equity perspective, but also a services perspective and both require funding flexibility. We are grateful for this historic investment in civil legal services and urge maximum provider flexibility to improve our ability to fill existing vacancies and provide desperately needed services connected to those vacant positions.

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

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<sup>&</sup>lt;sup>21</sup> www.iola.org

#### Summary of Responses from the Regional Long Term Care Ombudsman Programs "What would an increase in the Personal Needs Allowance Mean to You?"

\*The following are responses 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 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 by the brands that I want. I could by 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 life 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 somethings 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 1970s 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.