

Personal Care Attendant Working Group

Authorized under Ch 140 of the Acts of 2024

Finalized on February 28, 2025

Report due on March 7, 2025

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Table of Contents

1. Legislative Language
2. Group Overview
3. Group's Consensus Recommendations
4. Data Considered
5. Appendix

Some members wrote an individual statement reflecting their individual position. These individual statements represent the view of the person who submitted the statement.

1. Legislative Language

Line 4000-0601 of Chapter 140 of the Acts of 2024 provides that the executive office of health and human services shall convene a working group to review the scope of services and eligibility thresholds of the personal care attendant program;

provided further, that the membership of the working group shall include, but not be limited to:

- the secretary of health and human services or a designee;
- a representative of the personal care attendant workforce council;
- a representative of 1199 SEIU United Healthcare Workers East;
- a representative of the Massachusetts Senior Care Association;
- a representative of the Massachusetts Senior Action Council;
- a representative of The Arc of Massachusetts; and
- a representative of the Disability Policy Consortium;

provided further, that said working group shall evaluate the eligibility criteria, scope of services, program oversight, workforce supply and pipeline, short- and long-term cost growth, the current state of any structural change initiatives related to pre-admission counselling, screenings, assessments and coordination of care and any other component of the personal care attendant program **and make recommendations for the long-term sustainability and cost containment of the program;**

provided further, that said working group **shall submit said recommendations on or before March 7, 2025,** to the secretary of administration and finance, house and senate committees on ways and means and the joint committee on health care financing.

2. Group Overview

Group Members included:

- **Leslie Darcy**, MassHealth, Executive Office of Health and Human Services
- **Kristen McCosh**, The Personal Care Attendant Workforce Council
- **Becca Gutman**, 1199 SEIU United Healthcare Workers East
- **Tara Gregorio**, The Massachusetts Senior Care Association
- **Carolyn Villers**, The Massachusetts Senior Action Council
- **Maura Sullivan**, The Arc of Massachusetts
- **Charlie Carr**, The Disability Policy Consortium

Approach:

- The group met five times between October 2024 and February 2025 to discuss ideas and make recommendations for the long-term sustainability and cost containment of the program.
- The group requested information about the PCA program from MassHealth.
- The group reviewed data provided by MassHealth related to Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), Overtime, Program Growth and Utilization, Other LTSS programs, and how other states approach sustainability.
- The group deliberated extensively on the data that was provided and agreed upon 3 consensus recommendations.

3. Group Consensus Recommendations

1. MassHealth should enforce the overtime cap at 66 hours (\$6.7M savings)
2. MassHealth should ensure fraudulent activity within the PCA program is addressed
3. Eliminate managing PCA paperwork and PCA administrative work for members that do not have a live in exemption. *Rationale: members are required to use EVV unless they have a live-in exemption* (\$700k savings)

Further Work

To date, the workgroup agreed upon the above 3 recommendations, which would reduce spending in the PCA program by approximately \$7.4M or 0.46%. All members felt that with additional time, further work could be done, and additional consensus recommendations could be identified to support the long-term sustainability and cost containment of the program.

The workgroup has agreed to continue to voluntarily meet through June to work toward identifying additional consensus recommendations.

4. Data Reviewed by the PCA Workgroup

Growth in the PCA Program

The Personal Care Attendant (PCA) program served 56,000 members in SFY 24 (26,000 of whom are in managed care).

Our population is aging: According to data from the UMass Donahue Institute, between 2020 and 2030, we should expect a 29% increase in the population over 65 in Massachusetts.

The PCA program trajectory is unsustainable: The PCA program has grown from an annual cost of \$1.2B in SFY20 to *\$1.6B in SFY24 (+\$400M, a 32% increase) and is projected to reach \$2B by SFY27.

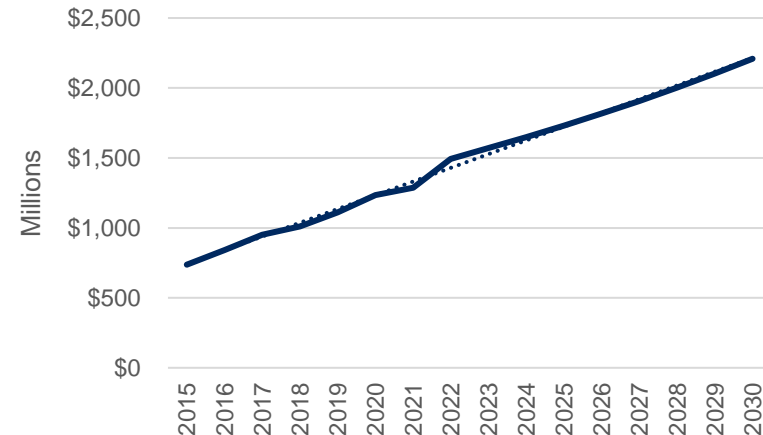
Between SFY20 and SFY24

- 7% utilization growth; \$90M of the \$400M
- 23% wage growth; \$310M of the \$400M

Comparison between 2015 and 2024

- Members (40K in 2015, 56K in 2024)
- Wage increase (\$13.68 in 2015, \$19.50 in 2024)

PCA Spending (2015 - 2030)



Program	SFY24 Spend (Fee-for-service and Managed Care)	Annual Spend change since 2015 (\$)
PCA Services	\$1.6B	+\$890M
Adult Foster Care	\$546M	+\$302M
Skilled Nursing Facilities	\$1.8B	+\$211M
Adult Day Health	\$214M	+\$96M
Day Habilitation	\$250M	+\$83M
Group Adult Foster Care	\$72M	-\$19M
Home Health	\$241M	-\$305M

Data Request - Hours Used by Age, past five calendar years

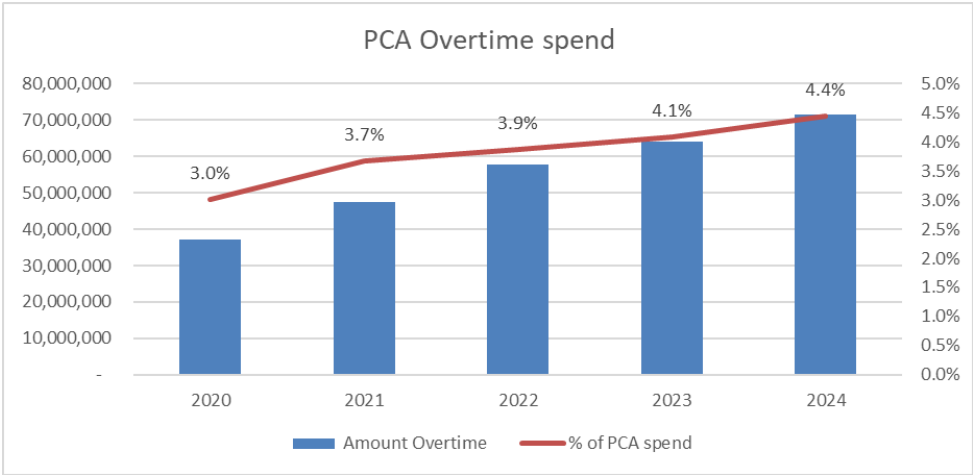
Number of Members					
Member Age*	2020	2021	2022	2023	2024
0-18	3,838	3,688	3,648	3,595	3,552
19-26	1,898	1,969	2,082	2,122	2,126
27-59	13,837	13,788	14,337	14,485	13,685
60-64	5,234	5,383	5,759	6,121	6,094
65-84	19,579	20,097	21,246	22,642	23,411
85 and up	5,439	5,649	5,799	6,089	6,129
Total*	46,255	47,084	48,610	50,421	50,839

Distribution by Total Hours Paid					
Member Age	2020	2021	2022	2023	2024
0-18	6%	5%	5%	5%	5%
19-26	4%	5%	4%	4%	4%
27-59	32%	32%	32%	31%	30%
60-64	10%	10%	10%	11%	11%
65-84	36%	36%	37%	38%	38%
85 and up	12%	12%	11%	12%	12%

Average Hours per Member					
Member Age	2020	2021	2022	2023	2024
0-18	938	970	958	946	916
19-26	1,484	1,500	1,457	1,471	1,453
27-59	1,478	1,516	1,499	1,532	1,565
60-64	1,200	1,228	1,231	1,258	1,264
65-84	1,162	1,183	1,175	1,217	1,165
85 and up	1,363	1,353	1,328	1,388	1,354
Total	1,369	1,390	1,394	1,436	1,397

Overtime Cap – The workgroup reviewed the cost of overtime and considered savings associated with a per week overtime cap

- In SFY 24 MassHealth spent **\$71M** on PCA Overtime.
- PCA Overtime Costs continue to increase year over year
- In 2024 MassHealth had 853 individuals that made over 75K/year. The 10 top PCA earners received between 170K and 204K/year.



<u>OT Hours Cap Per Week</u>	<u>CY23 OT Savings</u>
66 (26 OT Hours)	\$6,705,178
60 (20 OT Hours)	\$10,691,258
55 (15 OT Hours)	\$15,752,697
50 (10 OT Hours)	\$23,487,806

The workgroup reviewed LTSS Rate and Utilization Growth across multiple HCBS Services

Over the past 10 years, PCA is the only program with both significant rate and utilization increases

Program	Service Description	Spend				Rate				Utilization	Growth Comparison		
		FY 2015	FY 2024	Change in Spend Since 2015	% Change	2014	2026 Lower Projection	2026 Upper Projection	Rate Change (2014-2026)*	Utilization Change (2014 to 2024)	Rate	Utilization	Growth Driven by Utilization, Rate Increases or Both?
PCA	PCA Wage	\$738M	\$1.6B	\$890M	121%	\$13.38	\$22.52	\$25	87%	51%	↑	↑	Both
SNF	SNF Base Rate (PMPD rate)	\$1.6B	\$1.8B	\$211M	13%	\$188.42	\$289	\$309.23	64%	-26%	↑	↓	Rates
AFC	AFC	\$244M	\$546M	\$302M	124%	\$50.81	\$54.37		7%	109%	=	↑	Utilization
GAFC	GAFC	\$91M	\$72M	\$-19M	-21%	\$40.33	\$50		24%	-36%	↑	↓	Rates
Home Health	Nurse rate , 30 days or less	\$547M	\$241M	\$-305M	-56%	\$86.99	\$107.88		24%	-64%	↑	↓	Rates
	Nurse rate, 31 days or more					\$69.59	\$87.43		26%	-65%	↑	↓	Rates
	HHA - 15 min unit					\$6.10	\$10.18		67%	-74%	↑	↓	Rates
ADH	ADH Basic Level of Care (day rate)	\$118M	\$214M	\$96M	82%	\$58.83	\$106.32		81%	0%	↑	=	Rates
	ADH Complex Level of Care (day rate)					\$74.50	\$136.72		84%	-1%	↑	↓	Rates

*Using upper projection

The workgroup looked at the cost of the PCA Program and compared it to other HCBS supports

Cost	Aggregate cost - 2024	Per member cost
Tempus FI cost	\$48.1M	\$860.42 per year; \$71.70 per month
PCM, support for consumer employers	\$81.9M	\$1,462.67 per year; \$121.89 per month
Direct wages	\$1.41B	\$20 per hour (wage rate effective 7/1/25)
Federal and State Payroll Taxes	\$178M	\$2.05 per hour

Cost of 20 hours of PCA	Estimated Annual Cost in SFY 26
Wages + Taxes	\$22,932
FI cost	\$860.42
PCM cost	\$1,462.67
Total	\$25,254.62 per year, \$97.13 per day 5 days a week,

Cost of 40 hours of PCA	Estimated Annual Cost in SFY 26
Wages + Taxes	\$45,864
FI cost	\$860.42
PCM cost	\$1,462.67
Total	\$48,187.09 per year, \$132.38 per day 7 days a week

Program Cost of Alternative HCBS Supports (including admin)

Service	Cost	Supports	Eligibility
Group Adult Foster Care (GAFC)	\$50 / day	<ul style="list-style-type: none"> • Direct care provided by a direct care aide • Nursing oversight • Care management 	Member has a medical or mental condition that requires daily assistance with at least one ADL (bathing, dressing, toileting, transferring, mobility, or eating). Assistance may be (1) hands-on (physical) assistance, or (2) cueing / supervision throughout the entire ADL.
Adult Foster Care (AFC)	\$54.37 / day	<ul style="list-style-type: none"> • 24-hour supervision, and daily assistance with ADLs and IADLs by caregiver – must have a live in caregiver, caregiver is provided a stipend • Nursing oversight • Multi-disciplinary professional team • Care management performed by an AFC care manager 	Member has a medical or mental condition that requires daily hands-on (physical) assistance or cueing and supervision throughout the entire activity (bathing, dressing, toileting, transferring, mobility, or eating).
Home Health Aide	\$40.72/ hour	<ul style="list-style-type: none"> • Personal-care services, including assistance with ADLs • Services directly supporting nursing or therapy services such as simple dressing changes, medication reminders, and routine care of prosthetic and orthotic devices • IADL services are only authorized if incidental to an ADL task, generally not provided 	HH aide services are medically necessary when ordered by a physician or ordering non-physician and if provided pursuant to nursing or therapy services, or the member requires hands-on assistance with at least 2 ADLs

LTSS Program Cost Comparison (per day cost)

Level of Member Support	24 hours per day, 168 hours per week	8 hours per day, 56 hours per week	3 hours per day, 21 hours per week
PCA Cost	\$536	\$183	\$73
Group Adult Foster Care Cost	n/a	n/a	\$50
Adult Foster Care Cost	\$54	\$54	\$54
Home Health Aide Cost	n/a	\$326	\$122
Skilled Nursing Facility Cost Avg	\$254	\$254	\$254
Capital \$20			
Operating \$137			
Nursing \$132			
Patient Paid Amount (PPA) -\$35			

LTSS Program Comparison (annual cost)

Level of Member Support	24 hours per day, 168 hours per week	8 hours per day, 56 hours per week	3 hours per day, 21 hours per week
PCA Cost	\$195,483	\$ 66,7110	\$26,470
Group Adult Foster Care Cost	n/a	n/a	\$18,250
Adult Foster Care Cost	\$19,845	\$19,845	\$19,845
Home Health Aide Cost	n/a	\$118,902	\$44,588
Skilled Nursing Facility Cost Avg	\$92,710	\$92,710	\$92,710
Capital	\$7,300		
Operating	\$50,005		
Nursing	\$48,180		
Patient Paid Amount (PPA) -	\$12,775		

The workgroup reviewed how the MA PCA program compares to other states

	Massachusetts	California	Michigan
# of Consumers	56,000 FFS + Managed Care	500,000+	61,000+
Does State impose an overall cap on hours?	No, can receive more than 24/7 care; 168 + hours / week	Yes, 195 hours generally; 283 hours for severely impaired individuals / month 45 or 65 hours / week	Yes, can get exception 179.9 hours per month ~41.5 hours / week
Activities of Daily Living (ADLs) Cap <i>Hours per week</i>	No Cap <i>Below are Guidelines, which are exceeded</i>	Cap for overall hours (noted above)	Cap for overall hours (noted above)
Bathing / Dressing / Grooming	17	Included in cap above	6.10
Other health-related needs	30.75	Not covered	Cover specific complex tasks
Toileting	23.5	Included in cap above	3.25
Transfers / Mobility (includes passive range of motion)	65.5	Included in cap above	3.26
Walking / Ambulating	Built into transfers/mobility	Included in cap above	2
Eating / Feeding	14	Included in cap above	6.5
Medication	15.75	Available as an IADL	Available as an IADL
Instrumental Activities of Daily Living (IADLs) Cap: <i>Hours per week</i>	No Cap <i>Below are Guidelines, which are exceeded</i>	Cap for overall hours (noted above)	Specific IADL Cap of ~10 hours, Medication excluded
Shopping	1.5	Included in cap above	1.15
Cooking / Meal Prep	13	Included in cap above	5.77
Medication	Available as an ADL	Included in cap above	Covered
Special Needs/Equipment	No guideline	Included in cap above	Not covered
Laundry	1.5	Included in cap above	1.6
Housework/Housekeeping	1	Included in cap above	1.4
Transportation	No guideline	Included in cap above	Not covered
Managing PCA paperwork (differs between states)	No guideline	Included in cap above	Not covered

Where a monthly cap exists, we divided the number by 4.33 for ease of comparison to MA weekly guidelines
California information: https://www.cdss.ca.gov/agedblinddisabled/res/VPTC2/1%20Introduction%20to%20IHSS/History_of_IHSS.pdf; <https://www.bsa.ca.gov/reports/2020-109/introduction.html#:~:text=State%20law%20allows%20up%20to%20195%20hours%20per,of%20services%20each%20month%20for%20severely%20impaired%20individuals>.
Michigan information: https://www.michigan.gov/mdhhs/-/media/Project/Websites/mdhhs/Folder50/Folder7/MSA_21-52.pdf; <https://upcap.org/admin/wp-content/uploads/2022/05/MOS-Version-10-Highlighted-Version-pdf.pdf>

The workgroup discussed and considered restricting IADL support for members who live with their PCA

	Members who live with their PCA(s)	
FFS Only	# of Members with IADL hours	5,880
	% of Members with IADL hours and live-in PCA(s)	29%
	Average IADL hours per week	9.17
	Estimated Annual FFS IADL Savings	\$64M
	Estimated Annual IC IADL Savings	\$25M
	Estimated Annual Total IADL Savings	\$89M

The workgroup discussed and considered IADL caps

FFS Only	<i>IADL Category:</i>	Meal prep	Laundry	House keeping	Shopping	Equipment maintenance	Special needs	Med trans
	# of members with this category of hours	18,965	19,131	17,896	17,295	7,972	2,563	11,270
	Hours per week	133,677	19,696	15,924	17,660	2,807	696	5,331
	Average Hours per week	7.0	1.0	0.9	1.0	0.4	0.3	0.5
	Current Annual cost	\$158,138,966	\$23,299,662	\$18,838,346	\$20,891,111	\$3,320,104	\$823,618	\$6,306,151
	<u><i>With average hours per week as a category cap</i></u>							
	# of members with hours greater than the average	8,794	6,167	7,702	5,224	2,988	520	3,483
	Hours per week	116,367	17,308	13,839	15,612	2,131	548	3,226
	New Annual cost	\$137,661,521	\$20,475,195	\$16,371,328	\$18,469,037	\$2,520,862	\$648,796	\$3,816,449
	Estimated FFS Savings	\$20,477,445	\$2,824,467	\$2,467,018	\$2,422,074	\$799,242	\$174,822	\$2,489,703
	Estimated IC Savings	\$8,190,977	\$1,129,786.	\$986,807	\$968,829	\$319,696	\$69,928	\$995,881
	Estimated Total Savings:	<u>\$28,668,423</u>	<u>\$3,954,253</u>	<u>\$3,453,825</u>	<u>\$3,390,903</u>	<u>\$1,118,939</u>	<u>\$244,751</u>	<u>\$3,485,584</u>

Estimated savings across all categories:

FFS: \$31.7M

Integrated Care: \$12.6M

Total: \$44M

If IADL hours exceed ADL hours, lower IADL hours could be capped to match ADL Hours.

Some Consumers have more ADL hours than IADL hours.

3,359 Consumers* have IADL hours totals that exceed their ADL hours totals

IADL hours exceeding ADL hours ranges between **.2 to 14 hours weekly***.

If a Consumer could not have IADL hours that exceed their ADL hours, **anticipated savings are:**

FFS:	\$13.7M
Integrated Care:	\$5.5M
Total:	<u>\$19.2M</u>

*FFS consumers only

The workgroup looked at CommonHealth in the PCA Program

MassHealth CommonHealth offers health care benefits, similar to MassHealth Standard, to disabled adults and disabled children who are not eligible for MassHealth Standard.

In SFY24, about 6.2% of PCA members (3,500) were on CommonHealth.

In SFY24, CommonHealth accounted for 5.3% of total PCA Spend.

Population (based on plan type)	SFY24 Spend
Children	\$9.4M
Non-Working Adults	\$33.8M
Working Adults	\$42.1M
Total	<u>\$85.3M</u>

5. Appendix – See Attached Personal Statements from Group Members

Personal Statement of Kristen McCosh

I truly appreciate the opportunity I was given to join this Working Group in an effort to identify and recommend potential reductions in the cost of the Massachusetts PCA Program. As the designated representative from the PCA Workforce Council, my participation in this group has been guided by my lived experience as a disabled woman who has been a consumer-employer on the PCA Program for over 40 years.

I became disabled during high school, in 1983, when I sustained a C6 spinal cord injury in an accident that left me paralyzed from the mid-chest down. Since that time, I've been dependent on a power wheelchair for mobility and on PCAs for daily care.

As we all know, there is no way to prepare for the sudden onset of a severe disability. In an instant, my life was changed from a world of ease and privilege to a world in which I had no civil rights. As my acute injury morphed into a chronic disability, my family and I discovered a strong community of disabled advocates who were fighting for basic rights and services. The Independent Living movement was gaining strength, and the PCA Program was a revolutionary concept whose implementation was just beginning.

I wasn't old enough or mature enough to get involved in the IL movement at that time, but my family and I desperately needed services. The first service my parents helped me to enroll in when I got out of the hospital was the PCA Program - and it literally saved our lives: it allowed my parents to go back to work to support our family; it empowered me to gain the independence that all teenagers must; and it assured me that I had a place in my family home *rather than in a nursing home*. But even more than this, the PCA Program gave me hope for my future. I was able to move forward with my life and become a contributing member of society.

Four decades later, I am still an active consumer-employer on the PCA Program. There have been many changes in the program during this time period which have increased expenditures, including hard-fought-for PCA pay raises, holiday pay, earned time off, and training opportunities. The program has grown exponentially in terms of consumers and costs - but I believe this is a positive thing, both morally and economically. Morally, there is no argument to be made for institutional care over community-based care for people with disabilities who can live independently - full stop. Economically, the PCA Program offers an underappreciated return on investment by creating jobs: I alone have put literally hundreds of students through nursing school by providing part time PCA jobs during their college years! And thanks to my PCAs, I have been able to live independently in community, remain healthy, and work full-time for the past 33 years.

I fully understand that the Commonwealth of Massachusetts must make difficult decisions in order to be fiscally responsible, and I know that the PCA Program must be adapted in order to be sustainable. However, this program has the lowest overhead of any other Medicaid-funded home care program in Massachusetts, so it is a wise investment. With all this being considered, I want to reiterate my unequivocal support for the PCA Program for residents with disabilities. Any cuts or significant changes to this program should be minimal and made judiciously to have the least impact on disabled residents.

Kristen McCosh
City of Boston Disability Commissioner and ADA Title II Coordinator
Lifelong resident of Boston

Tara Gregorio

President of the Massachusetts Senior Care Association

Massachusetts has a robust set of long term services and supports (LTSS) and leads the nation in its commitment to supporting the state's aging adults and individuals with disabilities through its Community First policy. Among the various LTSS services offered is the Commonwealth's Personal Care Attendant (PCA) program. This consumer-driven program pays caregivers and/or family members to provide vital ADL and IADL services to over 50,000 beneficiaries living in the community. These services include many critical tasks such as bathing, dressing, meal preparation, shopping, medication management and more. While the program has financial and clinical eligibility criteria, it is vastly different from other LTSS programs that have greater consumer safety oversight, transparency in outcomes and fiscal accountability. As the PCA program continues to grow, the Executive Office of Health and Human Services may consider adding efficiency, quality, and transparency standards/metrics to ensure appropriate utilization of services.

In addition, as our over 65 population is projected to grow by over 15% or 218,000 individuals over the next decade (Source: UMass Donahue Institute V2024 Population Projections), it is critical that the Commonwealth funds all LTSS programs and not expand one service at the expense of cutting another. The stark reality is that access to care across all LTSS settings is only as strong as our ability to recruit, train and retain a stable workforce. The dedicated and compassionate caregivers who support our aging adults and individuals with disabilities are the backbone of the state's LTSS services, yet the ability to offer competitive wages depends entirely on government funding. This is particularly true since for most all LTSS programs, staff compensation is the single biggest driver of cost growth. It is therefore critical that we work together to support and adequately fund all LTSS services for consumers, their families and caregivers.

PCA Working Group Recommendations Statement

Rebecca Gutman; 1199SEIU Vice President for Home Care

On behalf of the over 85,000 healthcare workers of 1199SEIU who work in hospitals, health centers and nursing home facilities and the nearly 60,000 1199SEIU members providing a broad range of home care services as Personal Care Attendants (PCAs) for MassHealth enrollees, I offer this statement of recommendations for inclusion in the PCA Working Group's final report.

1199SEIU recognizes the importance of ensuring the long-term sustainability of the PCA program through judicious cost growth containment measures. However, we oppose the overly restrictive program growth cap proposed in Governor's Healey's "House 1" FY26 budget. Instead, we recommend that the PCA program stakeholders represented in this Working Group be given more time to continue working with EOHHS to more fully develop and reach consensus on the other more targeted reform ideas already being considered by the Working Group.

Background & General Position

The PCA program enables nearly 70,000 thousand people with disabilities, including many older adults, to choose to live independently in their own homes and communities. Absent these services, the health of many would decline and at least some PCA consumers would need to move to a skilled nursing facility and/or increase their utilization of hospital emergency care, both of which are already stretched thin due to capacity constraints and workforce challenges.

These outcomes would put even more pressure on already overburdened friends and family caregivers, other health care providers, and other state-funded services. If PCA consumers are forced to utilize more expensive forms of care due to PCA service cuts, it will cost the state more in the long run and add more burden to an already stressed healthcare delivery system.

Additionally, 1199SEIU's PCA members, the majority of whom are women of color, are returning both state and federal funds spent on the program directly back into the communities in which they live. PCAs are predominantly lower-income workers who use their paychecks for groceries, clothing and other essentials in stores in their neighborhoods. Moreover, this spending is done primarily in cities designated as equity communities by the state Department of Public Health. These areas housing large percentages of both PCAs and consumers include Boston, Worcester, Springfield, Brockton, Fall River, and Lawrence.

Unduly restricting the growth and future access to the PCA program will result in people with disabilities and elders losing service hours, potentially exacerbating already existing medical conditions, and putting more of a burden on family caregivers and healthcare facilities. Program cost growth is primarily the result of rising demand for these critical services and PCA wages moving closer to a living wage. Massachusetts should not put the burden of its current budget challenges on the backs of vulnerable consumers and low-income workers. Instead, with a record rainy day fund, and the option of raising new revenue by taxing large multinational corporations who hide their profits offshore, Massachusetts can avoid substantial home care service cuts and invest in the healthcare system our families and communities deserve.

Recommendations

1199SEIU has long supported targeted program integrity initiatives to end any fraudulent activity remaining in the PCA program. While the full implementation of electronic visit verification will likely help, we support EOHHS in all efforts to ensure that no consumer or PCA is receiving MassHealth payment that they did not earn or services for which they are not qualified.

We also have consistently advocated over the past decade for PCA program and state regulatory reforms designed to fully capture the federal match for all PCA program activities, including the PCA trainings and New Hire Orientation offered by the 1199SEIU Training Fund. Thirdly, we join in the Working Group's consensus decision to support keeping and more stringently enforcing the cap on overtime in the PCA program and considering the possibility of lowering the cap below the current 66 hours.

1199SEIU recommends that these three Working Group consensus reforms be implemented as soon as possible.

In the meantime, as discussed in more detail below, we oppose the Administration's FY26 budget proposal to impose a 3.6% annual spending growth cap on the PCA program. We believe this is an inappropriate and overly blunt approach - being applied to only one segment of our overall homecare, long-term care and health care delivery system - that fails to account for the growing needs of the state's aging population. It would also significantly hinder 1199SEIU members collective bargaining for a true living wage for the PCA workforce, an oft-stated goal of the Healey-Driscoll administration.

We ask for more time for EOHHS and this Working Group's stakeholders to work collaboratively on the cost containment ideas already under deliberation. Among the reforms discussed by the Working Group that 1199SEIU could potentially support upon such further review/discussion are:

- **PCA worker overtime:** Lowering the overtime cap to a level below the current 66-hour cap.
- **Meal Prep & IADL:** Reform that limits meal prep time and/or authorizations for Instrumental Activities of Daily Living (IADLs like shopping or housekeeping) for consumers with less than 10 hours of authorized services. While these services are critical for many consumers, we are committed to bringing this potential reform to our PCA leadership for discussion.
- **Administrative Savings & Fraud Prevention:** 1199SEIU certainly supports all efforts to streamline PCA program processes to reduce administrative costs at MassHealth and Tempus. While the PCA program already has significantly less "overhead" and lower administrative costs than nearly every other health care provider or state government program, more can always be done to reduce costs in these areas.

Opposition to a Firm Growth Cap

The Governor's proposed growth cap is the wrong approach. The FY26 budget proposal to apply a firm and indefinite annual 3.6% cost growth cap to just a single LTSS program (the PCA program) and allowing EOHHS to unilaterally impose program reforms through regulations is inconsistent with the way the HPC currently manages their cost growth benchmark.

The Health Policy Commission's 3.6% cost growth benchmark is part of a broader process with the ambitious goal of bringing Massachusetts' health care spending growth in line with growth in the state's overall economy. The benchmark is a statewide target for the rate of growth of total health care expenditures that was never intended to be utilized as a firm cap on any one provider, payer, service or program. If a particular provider or payer's spending significantly exceeds the benchmark, the HPC first conducts a robust review of all referred organizations to understand the drivers of health care spending, and to encourage greater efficiency. A formal Performance Improvement Plan (PIP) to lower costs is very rarely required and then only of an organization where the HPC both identifies "significant" concerns regarding that organization's spending performance and finds that a PIP could result in meaningful cost-saving reforms.

If a benchmark is going to be established, it ought to be a more flexible goal (rather than a firm cap) for PCA program cost growth. Further, in comparing performance of the PCA program against such a benchmark, due consideration ought to be given to both utilization increases that are driven by growing need as well as cost growth in other state-supported LTSS programs. If such a review demonstrates unsustainable growth in the PCA program, legislative and regulatory reform recommendations should be developed by a group of program stakeholders rather than simply imposed through amended EOHHS regulations.

Conclusion

While we are committed to sustainable cost growth for the PCA program, it's important to note that much of that growth is the understandable result of an aging Massachusetts population and growing demand for consumer-directed home care services.

Operating for more than 50 years, the Massachusetts PCA program has proven itself as the most effective, cost-efficient and popular home care program in the Commonwealth. PCAs enable tens of thousands of seniors and people with a disability to live independent, productive lives in the settings of their own choice. Moreover, the PCA program infuses over \$1 billion annually in state dollars into Massachusetts communities, an investment in quality jobs that also helps consumers return to the workforce and enables PCAs to move up the health care career ladder.

Accordingly, we look forward to continued work with the Administration, the Legislature, our consumer advocate allies, and all PCA program stakeholders to limit cost growth and ensure that the long-term sustainability of this critically important program.



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Janet Sweeney Rico, Ph.D.
President

Maura Sullivan, MPA
Chief Executive Officer

Personal Care Attendant Program Commission

To: Leslie Darcy, Chief of the Office of LTSS, MassHealth

From: Maura Sullivan, CEO, The Arc of Massachusetts

Date: 2/16/25

Subject: Sustainability of the MA PCA program

It is a privilege for The Arc of Massachusetts to be included in the PCA working group and to meet regularly on this topic with advocates and MassHealth leadership. It has been valuable to share the critical importance of the PCA program, while acquiring a deeper understanding of the exponential growth of the program. The group focused on developing recommendations and strategies regarding sustainability, responding to current projections that show the PCA program outpacing Health Policy Commission growth limits.

The Arc is the leading advocacy organization for people with intellectual and developmental disabilities, including autism and their families, representing over 200,000 people across the state. Our mission is to enhance the lives of people with disabilities, through advocacy for community services and supports that foster inclusion, self-determination and equity across all aspects of society.

The Arc has been an advocate for the PCA program since its inception and helped push for needed expansions in eligibility and access. Our advocacy is centered on inclusion, independence, and ensuring that people with disabilities have the same opportunities as anyone else to live their lives with dignity and respect. Last year, The Arc was instrumental in stopping proposed cuts to the PCA program through advocacy with the legislature. We are grateful to see the program fully funded for FY'26. With the current workforce shortage crisis in day and residential programs for people with autism and IDD, it is even more critical that this cost effective, community based, self-directed program remains a strong, viable option in the Commonwealth. Importantly, the PCA program provides individuals and families the opportunity to hire and train their own employees, to have control over their lives and saves immeasurable costs verses a segregated setting, like a nursing home.

Our advocacy has focused on the growing numbers and needs of our community. The numbers of individuals graduating from our schools with autism and IDD has doubled in the last decade. The needs of many in our community are continuing to become more complex and dynamic. We are grateful that this administration acknowledges the growth of the disability population



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that would utilize PCA services including aging adults, a population that is living longer with more chronic disabilities, more individuals with autism and complex medical conditions. The need for community and home based supports is clearly expanding across the state and the nation.

Working with the Chief of the Office of LTSS, Leslie Darcy and the community leaders and advocates on the working group, a consensus developed around overtime enforcement.

I am in agreement with enforcing the overtime policy and recommend the following:

1. MassHealth should focus on limiting the growing use of excessive overtime, as this could be a substantial cost-saving strategy. We examined the data and the historical policies and agreed that enforcing a 66 hour cap is wise for cost saving as well as safety. 88% of overtime payments are not authorized and overtime spending has grown over 1.5% in the last 4 years. There are concerns regarding safety and medical errors when a PCA works prolonged hours.
2. MassHealth should continue to monitor for fraud within the program and produce and share data to show the effects of the EVV system and any other strategies to improve efficiencies and detect fraud.
3. MassHealth should continue to monitor other successful initiatives for sustainability in other states that do not cut back eligibility or pay structure and bring these ideas to stakeholders.
4. MassHealth should continue to work on efficiencies within the program in terms of use of technology when possible. Potentially utilizing virtual evaluation strategies when possible and desired by the consumer, for people who have consistent PCA hours and insignificant eligibility changes annually.
5. When the Governor's administration and the Health Policy Commission consider the future budget for PCA programing, they should closely weigh the costs of more expensive models that are also more segregated. If the PCA program exceeds the benchmark growth set by the commission, resorting to cuts could create alternatives that in the end would be more expensive to the state.
6. The Governor and the administration should consider using any new tax revenues for programs to support the growing number of people with disabilities, as a priority as we have seen with education, transportation and infrastructure.



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7. MassHealth should work closely with The Arc to solicit survey responses from the broader PCA community to potentially discover where more efficiencies could be made and where problems can be more easily resolved.

Thank you for the opportunity to comment on the sustainability of the PCA program. PCA services are a lifeline for thousands and without a robust program, the Commonwealth would see more spending and greater costs in more segregated, expensive settings.

Maura Sullivan, MPA
CEO, The Arc of Massachusetts

PCA Working Group Statement - Charlie Carr

Legislative Liaison, Disability Policy Consortium

I appreciate the opportunity to join the PCA Working Group, and contribute and discuss ideas about the long term sustainability and cost containment of the PCA program. I have been active in the independent living and disability rights community for nearly 50 years. I was institutionalized for seven years in my youth, where I saw firsthand the dangers of a lack of choice and autonomy.

In 1974, the PCA program started with 15 openings for members. 10 of those openings were for transitional living, and five were for the living in the community. I was one of those five. I have seen the program grow over this time. The growth has been staggering, along with the bureaucracy that's followed. While the cost has grown, the program is still less expensive than other programs on a per member basis. Compared to other LTSS programs and nursing homes, it is very cost-effective. The program gives control to the consumer-employer to hire, train, and if necessary, fire PCAs. The program also allows the consumer-employer to choose whether they want to live in an institutional setting, like a nursing home or, integrate into the community like most of society. This is not the case with other LTSS programs and certainly not nursing homes.

Overall, growth of the program is a positive in many respects. Cost is certainly an issue, but this is a vital program that has been and continues to be driven by the independent living philosophy since its inception in 1974.

I, and others, want to be able to control our lives and make the choices we want. This isn't as easy to do in other programs. And, I recognize the importance of sustaining the PCA program. Based on the Working Group's discussions over the past several months, I would like to put forward the following recommendations and items that warrant further discussion.

Recommendations:

- **Enforce Cap of PCA Overtime at 66 hours.** Enforce the current cap. 66 hours is a reasonable period of time for a PCA to work with their Consumer-employers. This was set during the last administration.
- **Eliminate managing PCA paperwork and PCA administrative work.** These tasks are not authorized in other states. And, paper timesheets do not need to be faxed given the use of e-timesheets and Electronic Visit Verification (EVV). This is projected to save \$1M/year.

Moving forward, the group should discuss:

- **An ADL hours requirement threshold for program participation or IADL hours.** There are some members who have only a few ADL hours, but have many more IADL hours. The group should discuss the right ADL hours threshold. One idea is to tie the number of IADL hours

to ADL hours. For example, a member cannot receive more than 2 hours of IADL support if they have 2 hours of ADL support. Or, eligibility may be tied to ADL hours. If members need primarily IADL support, homecare may be a more appropriate service for them.

- **A program growth benchmark:** The Governor has proposed tying the PCA program to the Health Policy Commission (HPC) benchmark. I am not convinced that this benchmark is the best way to go, but we need to have more discussion about what an appropriate measure would be. The group should look at alternatives and discuss. If the group cannot find something that is agreeable to everyone, then we should abandon this idea.



Statement for PCA Working Group

Submitted by Carolyn Villers, Executive Director

I present this statement on behalf of the Massachusetts Senior Action Council, a grassroots organization led by seniors that empowers its members to use their voices to collectively address policies and systems that impact their health and well-being. I appreciate the opportunity to serve as a part of this work group, as our membership is deeply committed to the long-term sustainability of the PCA program, which is essential for the Commonwealth's ability to offer community-based long-term care.

When I began as a community organizer with Mass Senior Action Council nearly 20 years ago, over 70% of the state's long-term care spending went to institutional-based care. Seniors, people with disabilities, and their families fought tirelessly to change this, advocating for the ability to receive care in their communities. The Commonwealth has made significant progress towards a community-first approach, but more work is needed to ensure that those who require long-term care can receive care in a setting of their choice. A robust PCA program is crucial to achieving this goal.

I thank the MassHealth team for their prompt response to our data requests. This information helped the workgroup gain a deeper understanding of the PCA program as we considered various proposals. **It was particularly revealing to discover that over 60% of those enrolled in the PCA program are over the age of 60.** This fact provides valuable insights into the program's past growth and is crucial for understanding its future trajectory. The population of individuals who will require long-term care as they age is rapidly growing and it crucial that we invest in a system of support that can meet this growing demand.

Mass Senior Action is committed to ensuring that quality care is provided across the long-term care continuum. Investing in our frontline workers is of utmost importance. Direct care human services workers remain an underpaid and undervalued workforce. We firmly believe that quality care is intrinsically linked to quality jobs. As we consider program sustainability, we must prioritize investing in our workforce so that caregivers feel valued and have livable wages.

One recommendation that our work group unanimously agreed upon is the enforcement of the existing overtime cap. The group also pledged to evaluate further restrictions. This cost-saving measure helps to safeguard workers and their consumers. Still, it must be accompanied by a commitment to building the workforce to ensure they can meet the escalating demand.

Mass Senior Action strongly opposes the Administration's proposal to use the Health Policy Commission growth benchmark as a cap for future PCA program growth. The HPC benchmark is designed to look at healthcare spending as a whole – across providers, as well as public and

private payers. Furthermore, it is not intended to serve as a cap, but rather as a goal to help ensure ongoing examination of cost trends and to guide thoughtful policy. The healthcare system provides opportunities to make upstream investments in preventive care that can avoid more costly treatment. The PCA program does not offer these same opportunities. In fact, many argue that investing in PCA care is avoiding more expensive institutional care. We believe it would be inappropriate to apply the HPC benchmark to a single program that serves a growing population with increasing needs. We are not opposed to developing a growth benchmark that can help evaluate program integrity and efficiency, but feel firmly that said benchmark must be intentionally designed with the PCA program in mind and must incorporate a way to assess any cost shifting to other LTC or healthcare programs.

The workgroup has committed to continue meeting in the months ahead to identify other areas of consensus. As we continue in this work beyond the legislative mandate, and as other stakeholders evaluate proposals, we caution against proposals that would undercut any progress made towards supporting individuals to live, work, and age in their communities.

Again, we appreciate the opportunity to serve on this workgroup and look forward to continuing to work with stakeholders in developing a comprehensive long-term care system that prioritizes dignity for caregivers and consumers.