Closing the Gap: Maine's Direct Care Shortage and Solutions to Fix It



By Arthur Phillips, Economic Policy Analyst Maine Center for Economic Policy June 17, 2024



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Executive summary

Today in Maine, thousands of older adults, people with disabilities, and individuals with behavioral health challenges do not receive the personal care and support services they qualify for through state and federal programs. For example, over 23,500 hours of approved home care for older adults go undelivered each week while others seeking care outside these programs also struggle to get the support they need. To secure the health of Maine residents and our economic stability, we need bold solutions to the critical problems in our direct care system.

In 2023, Maine Center for Economic Policy (MECEP) published *The High Cost of Undervaluing Direct Care Work*, a report highlighting how low pay and poor benefits lead to high poverty, turnover, and burnout among direct care workers. These realities have far-reaching economic consequences for providers, consumers, and family members, impacting Maine's workforce, public revenue, and economic vitality by limiting people's ability to participate fully in our economy.

Closing the Gap: Maine's Direct Care Shortage and Solutions to Fix It aims to estimate Maine's "care gap" — the disparity between the care needed and available. This report builds on MECEP's previous work to support efforts by academics, advocates, consumers, state health officials, policymakers, and providers to address issues that impact our direct care system. By quantifying the current care gap, what it will take to address it, and the costs of inaction, we hope to bring these issues into greater focus and identify solutions.

MECEP estimates:

- Maine needs more than 2,300 additional full-time workers to bridge the gap between the care people are entitled to and approved for and what is available. This conservative estimate does not include behavioral health staff or account for the much larger number of workers who leave direct care jobs each year.
- Maine needs to raise the MaineCare reimbursement rate for the labor portion of direct care supports and services to at least 140% of the state minimum wage to compete in the current labor market.

Addressing direct care workforce challenges will require a comprehensive approach including:

- Collaboration and engagement by policymakers with direct care workers, consumers, and advocates on developing policies that address these workforce issues.
- Enhanced job quality through better wages, benefits, training, scheduling, and respect, especially during a period of economic growth and historically tight labor markets. Despite some progress in recent years, direct care workers continue to earn less than people in other jobs with similar entry-level training. Proper commitment to and reimbursement of public dollars and fixing how rates are passed to workers are key to attracting and retaining staff.
- Improved data collection. Data driven efforts are essential for tracking and meeting Maine's care needs, and to be effective they must be paired with engagement of workers, consumers, public agencies, and advocates to identify and implement solutions and design a system to track progress over time.

Maine faces a significant care gap



While many of our neighbors and family members struggle to get the care they need, there is no comprehensive data that provides a full picture of the extent of the problem. Part of the challenge is that care is delivered through a variety of programs and in a variety of settings. Another challenge is a lack of state-level investment in a comprehensive, accessible, and integrated system that can give policymakers, program administrators, consumers, and providers the information they need to make informed decisions.

In recent years, the state has made improvements by reporting on access to care in a few ways, including in an annual report that provides a snapshot of capacity in nursing and residential facilities and in home care and a <u>quarterly dashboard</u> on waitlists and how long it takes consumers to receive services. This report attempts to provide a more granular understanding by depicting care gaps associated with:

- Approved care not being delivered
- Declines in nursing and residential facilities and beds
- Service gaps and years-long waitlists for people with intellectual and developmental disabilities
- High employee vacancy rates and long waitlists for organizations serving people seeking behavioral health services

Many of our neighbors and family members struggle to get the care they need.

Approved care not being delivered

Each year, the Maine Department of Health and Human Services' Office of Aging and Disability Services (OADS) releases a report that provides insight into Maine's care gap associated with certain state and federally funded programs.¹ After some progress coming out of the pandemic, the most recent edition suggests a growing care gap. MECEP's analysis of the underlying data for this report reveals more than 23,500 unstaffed hours per week for older people in need of home care through state-funded and MaineCare programs. Closing that care gap would require roughly 400 additional full-time personal support specialists and another 187 nurses.

In nearly all state-funded and MaineCare programs that support older people, the percentage of enrolled members receiving less than all their approved hours of care and supports dramatically increased in 2023. In the state-funded Section 63 program² providing in-home and community support services, additional enrollment may have mostly driven this. Yet other programs saw relatively flat numbers of individuals approved for supports and services but increasing numbers receiving less than their approved hours.

In the Section 19 program, home and community benefits for older people and adults with disabilities, the portion of active members who received less than their approved care rose from about one-third to around half. These are nursing-home-eligible consumers who have exercised their legal right to receive care in their home. To be eligible for MaineCare nursing home care, a person must have significant medical needs and extremely low income. In December 2023, there were about 570 more people receiving less than their approved care than the previous year.

For the Section 96 program, a MaineCare program providing nursing and personal care services, the three-year average in 2020-2022 of about 46% of enrolled members not receiving all approved care jumped to 62% in 2023. That means about 430 more people were receiving less than their fully approved care in December 2023 than were a year earlier.³

The care gap reflected in OADS' annual report is a helpful snapshot, but newly available data⁴ from the state's three service coordination agencies paints a more comprehensive picture. There were more than 16,000 weekly hours of personal support specialists and more than 7,000 weekly nursing hours going unstaffed. The data provided at the county level shows that, relative to total population, **the greatest needs were in Somerset, Washington, Kennebec, Aroostook, and Hancock counties.** This suggests that to close the care gap among these three programs of long-term supports and services, we need roughly 400 additional personal support specialists and another 187 nurses.

An additional care gap exists between the unstaffed hours Maine's service coordination agencies report to the state, and the number of hours of care that provider agencies are in fact able to deliver. Service coordination agencies receive referrals from the state for individuals who are approved for certain levels of care. Coordination agencies refer those needs to provider agencies, which operate throughout the state and employ the direct care professionals who deliver the approved services. However, those providers often cannot deliver all the services referred to them, whether due to staffing shortages or other unforeseeable hurdles. A more accurate picture of the care gap would measure the difference between the number of approved care hours under each program and the number of hours which are delivered and for which the state reimburses. While

this data does not appear to be currently tabulated, doing so should be achievable.

Additionally, OADS' annual report notes that as of December 2023, there were 1,312 people on the waitlist for services under Section 69, an independent support services program. Other programs do not currently show a waitlist; however, service coordination agencies have reported they are not accepting new referrals for Section 96 due to costs far outpacing reimbursement rates. OADS' report does not reflect a waitlist for Section 96 as of December 2023, which raises questions about whether new members are being enrolled and receiving the supports they need.

Between existing waitlists and the referred services which are never delivered, the gap in home care capacity is certainly larger than the 23,500 weekly hours noted above.

Decline in facilities and beds

There has been a trend from receiving long-term care in nursing homes and other residential facilities toward an increasing desire to age at home. At the same time, Maine's aging population demands more nursing and residential care than is available. The cost of operating nursing homes, including labor costs required to recruit and retain sufficient staffing, have risen faster than state reimbursement rates, contributing to closures across the state.

According to analysis by the Boston Federal Reserve, from 2010 through 2023 Maine lost 19% of its nursing homes, more than any other state in New England, and served 21% fewer patients. Hancock, Waldo, and Lincoln counties lost between 60-100% of their available nursing home beds. By comparison, roughly 5% of nursing homes nationwide have closed over the same period.

Maine Department of Health and Human Services (DHHS) data shows the statewide nursing facility bed count declined by 381 beds from November 2020 to October 2023, and the overall number of nursing facility beds has declined each year since 2020. Over that period the state had 479 fewer beds serving MaineCare members.

In addition to the loss of available beds, the percentage that is occupied has declined primarily due to a shortage of direct care workers. Before the pandemic, nursing facility occupancy was above 90%. It fell to a low of 74% by late 2021 and early 2022 and

sat at nearly 82% as of February 2024.⁵ One primary driver of these challenges is MaineCare rates have not kept up with the cost of providing care. According to the Maine Health Care Association, 2022 data showed a \$96.5 million MaineCare shortfall, while the residential care shortfall was \$24.3 million. In addition to MaineCare underfunding and a workforce shortage, nursing facilities have had to increasingly rely on costly temporary staff agencies to help maintain staffing levels.

A result of the shortage of nursing home beds is the increased strain it places on hospitals. An <u>estimated</u> 200 people are stuck in Maine hospitals each day who could be discharged to a nursing home. Maine Medical Center in Portland alone estimated between 60 and 70 patients each day awaiting nursing home placement. Northern Light Health estimated that over a six-month period in 2022-23, the cost of such delayed discharges amounted to \$13.6 million and approximately \$63,000 per person. These delays reduce hospitals' capacity to offer acute care, increase costs for our health care system, and are associated with poor mental and physical health outcomes for people in need of long-term care.

The minimum additional nursing home capacity needed to enable Maine's hospitals to discharge patients ready for nursing home care is about 200 beds. Assuming the average of 4.48 hours per resident day, this would require 157 more workers, though the true number of additional staff is almost certainly greater.

Care for people with intellectual and developmental disabilities

Maine Association for Community Service Providers (MACSP) represents organizations providing support and services to people with intellectual disabilities, autism, and brain injuries in a variety of settings. In January 2024, MACSP surveyed their membership to measure the unmet needs due to

The leading role for New Mainers:

PHI points to research that shows immigrant workers are more likely than their US-born counterparts to stay in the long-term care workforce, and higher immigration is associated with better staffing and a higher quality of care.

a shortage of workers. The survey was completed by 25 organizations, which serve more than 1,700 people with intellectual or developmental disabilities approved for support and services through MaineCare or state-funded programs.⁶

The survey found significant staffing shortages in each service area. Based on these results, MECEP estimates that Maine would have to add nearly 1,600 workers to close the service gaps faced by adults with intellectual and developmental disabilities. The following is a breakdown of the estimated need for full-time equivalent workers (FTEs) by type of service:

- Group homes: 488 FTEs
- Quarter hour home support: 286 additional FTEs
- Community supports: 812 additional FTEs

These findings align with what has been found at the national level. ANCOR's <u>State of America's Direct</u>. <u>Support Workforce Crisis 2023</u> reports the findings of a survey of 581 organizations delivering services in 45 states and Washington, DC, and found:

- 95% reported experiencing moderate or severe staffing shortages in the past year
 - 77% turned away new referrals due to ongoing staffing shortages
 - 60% were likely to further discontinue programs and services
- 74% delayed launching new programs and services in 2023
- 72% experienced difficulties achieving quality standards due to insufficient staffing

Public data updated every quarter showed that as of March 2024 there were 2,451 people with developmental disabilities or brain injuries on waitlists for public supports and services, equivalent to about 42% of people currently enrolled in those programs. The waitlist for people with intellectual disabilities and autism spectrum disorder seeking services provided under Section 21 is between 6.1 and 7 years. Most people waiting years to enroll are receiving some level of other coverage.⁷

Behavioral health providers

In January and February 2024, the Maine Behavioral Health Access coalition conducted a point-in-time survey of providers to better measure the shortages impacting the sector. Three hundred twenty-seven responses came from large behavioral health organizations and individual behavioral health providers in every county of Maine.

Among the 50 organization respondents who reported both the number of clients waiting and wait times, the survey found:

- 8,812 clients were waiting for mental health counseling from organizational providers for an average wait time of 32 weeks
 - 69% of clients wait for counseling from organizational providers for 10 months or longer, including 23% who wait for longer than 1.5 years

- 2,819 clients were waiting for psychiatric care for an average of 33 weeks
- 1,340 clients were waiting for case management services for an average of 25 weeks

Among the 227 independent provider respondents who reported both the number of clients waiting and wait times, the survey found:

• 1,099 clients were waiting for care from an individual provider for an average of 33 weeks

Organizational respondents also reported high vacancy rates, defined as the number of vacancies divided by the total full-time equivalent employees plus vacancies. The vacancy rate for mental health clinicians exceeded 20%, while the rate for case managers was about 15%. Among individual providers, 40% are aged 60 or above, two-thirds of whom plan to retire within 10 years.

Workforce shortages are at the heart of Maine's care gap



Demand for these services will only continue to grow while the pool of workers will likely continue to shrink.

There are many complicated reasons for Maine's care gap, but the greatest is staffing. From one year

before the pandemic through September 2022, there were approximately 4,400 fewer workers in direct support industries, according to an analysis by Maine Department of Labor's Center for Workforce Research and Information (CWRI).8 MECEP's analysis of Maine's care gap reflected in the previous section identifies the need for at least 2,300 staff to address the existing, known need for care.

Despite fewer workers, Maine's demographics mean demand for these services will only continue to grow while the available pool of potential workers will likely continue to shrink. Between 2017 and 2021, our population aged 65-74 increased by more than 25,000. The share of Maine people aged 65 or older is projected to grow from 22% in 2020 to 29% by 2050, when the national average is expected to be just 21%. Over the same period, the ratio of people aged 20-64 to people 65 and older is projected to decline from 2.6 people in 2020 to 1.8 in 2050.

To account for these realities, CWRI has projected an increase of nearly 2,000 home health aides, personal care aides, and nursing assistants by the year 2030

compared with 2020 levels.¹⁰ The US Bureau of Labor Statistics <u>projects</u> one of every six new jobs created in the US between 2022 and 2032 will be in direct care

A much larger number of positions will need to be filled due to turnover. One national survey estimates the annual turnover rate for direct care workers at 64% or higher. To address the need for new workers and fill positions created by high turnover, PHI estimates the total direct care job openings in Maine from 2020 to 2030 at 35,500.¹¹

Worker turnover may cost Maine direct care providers more than \$90 million each year.¹²

Research suggests providers' turnover costs to be between 20-40% of a direct care worker's annual income per vacancy. This is due to the direct costs of separation, vacancy, replacement, and training, which induce higher rates of overtime, temporary workers, and injuries. Additional indirect costs include lost productivity, reduced quality, lost reimbursement revenue, and lost clients.

Low wages for care workers are a key contributor to continued worker shortages



Direct care workers identify fair pay as the primary element to retaining and recruiting workers.

Maine's Essential Care and Support Workforce Partnership, of which MECEP is a member, surveyed 300 current direct care workers about what could be done to attract more people into the profession. Respondents could choose between fair pay, quality training, quality supervision and support, respect and recognition within their organization, access to professional development, and other. Nearly two-

thirds (64%) chose fair pay, with the next highest selection being access to professional development (9%). About six in 10 respondents cited fair pay as the most important element to *retaining* direct care professionals, followed by access to professional development (10%) and respect and recognition within their organization (9%).

This corroborates findings from the <u>focus groups</u> Maine's Long-Term Care Ombudsman Program conducted in late 2021 with more than 700 direct care workers, most of whom expressed their pay was not commensurate with the difficulty and importance of their work. Adequate staffing, itself impacted by compensation, was also another top concern.

Comparing wage levels and wage growth of direct care workers to similarly placed workers in the economy validates these findings and provides a clearer picture of the pay gap faced by care workers. PHI's latest State Index finds that as of 2022, Maine's direct care workers earned an average of \$1.92 cents less per hour than workers in occupations with similar entry-level requirements. This was an improvement from 2020, when PHI found median wages for Maine's direct care workers were \$2.36 less than occupations with similar entry-level requirements, and 10 cents less than occupations with lower entry-level requirements. As of May 2023, home health and personal care aides had a

lower median wage than cooks, customers service representatives, janitors, secretaries, and social and human services assistants.¹⁵

Based on the latest wage comparison to other jobs with similar entry-level requirements, direct care workers' median wage should be at least 140% of minimum wage to be competitive. Accounting for working conditions which contribute to very high turnover rates, wages may need to rise even more to meet all Maine people's needs.

The 140% minimum wage threshold reflects what is needed to make direct care jobs more competitive in Maine's labor market. However, it still falls short of a living wage — what an individual must earn while working full time throughout the year to support themselves and their family. Living wage calculators

use different methods to account for which expenses are essential, but generally they reflect conservative estimates of how much money people need to survive without relying on publicly funded programs.

One prominent example is the Massachusetts Institute of Technology Living Wage Calculator. According to this tool, the living wage for a person in Maine who lives alone with no dependents is \$22.04, or \$4.65 more than the median wage for a home health aide and \$2.23 more than the 140% threshold. The living wage for a person with one child is estimated at \$39.21 — one in four direct care workers in Maine have at least one child under 18 years of age.

Recent state action has helped address the issue of low wages in the short term



Maine leaders have taken significant steps in recent years to address direct care workforce challenges.

Maine leaders have taken significant steps in recent years to address challenges facing the direct care workforce. The 2019 Long-Term Care Workforce Commission convened experts, advocates, and impacted people to learn and deliberate over

potential solutions. That work resulted in a series of recommendations, many of which were set in motion, including a recognition that wages were too low.

In 2021, the legislature enacted a measure to require the labor portion of MaineCare reimbursement rates for all direct care workers in all settings to be set at 125% of the state minimum wage. This was a significant step forward, though not without its challenges — the original recommendation was a minimum wage of at least 125% of minimum wage, while the resulting reimbursement structure allows providers to pay some workers less than that amount to avoid wage compression while balancing the need to recruit new workers. Data shows that in 2022, more than 1,000 direct care workers were hired at wages below 125% of the minimum wage. 16 An updated reimbursement structure that sets a minimum wage and reimburses at higher rates for workers with longer tenure could ameliorate these issues.

Direct care workers also got a substantial temporary financial boost in 2022 thanks to the American Rescue Plan. The Mills administration directed more than \$120 million in federal funds to recruitment and retention bonuses for home and community-based care providers as part of the Maine Jobs and

Recovery Plan. Maine DHHS distributed bonuses to more than 24,000 direct care workers, including nearly 19,000 existing workers and more than 5,500 new recruits. Recognizing the deeply destabilizing impacts the pandemic had on our direct care infrastructure, these bonuses were intended to shore up the system by growing and stabilizing the workforce. Provider agencies were left to determine policies for setting bonus amounts, which they were required to share with workers. Based on data DHHS collected from recipient agencies, the bonuses for existing workers averaged \$3,429 and the median was \$2,850 — while 5,850 workers received recruitment bonuses with a median value of \$1,634, and 20,928 received retention bonuses with a median value of \$3,600.17

These bonuses were associated with a significant recovery in the direct care workforce through the end of 2022. Between March and December 2022, nearly 300 agencies reported growing their workforce by more than 3,500 people, or more than 20%. As of June 2023, nearly 82% of workers who received a bonus remained employed at the same agency by the end of the period during which they reported results to DHHS.

Data provided to MECEP shows that among workers who received a bonus of \$5,000 or more, 90% were employed at the end of the reporting period. Among workers who received below-median bonuses (up to \$2,850), approximately 74% were employed by the end of the reporting period. These figures suggest a remarkable improvement from national turnover

averages. One <u>study</u> of nursing homes across the US found the median turnover rate in 2017-18 to be nearly 100%, while a <u>survey</u> of the national home care sector reported professional caregiver annual turnover fluctuated between 64-82% from 2017 to 2022. Since these were one-time grants that coincided with the implementation of the 125% care worker reimbursement, more research is needed to assess the longer-term impacts of these efforts.

In addition to these efforts, Maine DHHS, along with the Area Agencies on Aging, created the Respite for ME pilot program, which for two years provided up to \$2,000 in reimbursements to family caregivers for approved expenses including respite care, counseling and training, financial guidance, and assistive technology. Following the program's success, lawmakers extended it and raised the grant cap to \$5,171 per caregiver.

Another bright spot has been the Maine Long-Term Care Ombudsman Program's Direct Care and Support Professional Advisory Council. The Council engages direct care workers, many of whom have decades of experience in the field, in identifying ways to address workforce challenges. The Council could in the future provide formal recommendations to policymakers on ways to improve working conditions and make it more attractive for care professionals to seek long-term careers. Maine also launched the Caring for ME campaign in April 2022, an effort to recruit workers into the direct care field through digital outreach, sector-specific job fairs, and offers of free training.

Data challenges make it difficult to get a complete picture of Maine's care gap and the effectiveness of solutions



The care gap analysis does not capture people who choose not to pursue care, who don't qualify for MaineCare, or workers who drop out of the workforce to care for a loved one.

MECEP's attempts to measure Maine's care gap gives only a partial view of the full scope of the problem. The care gap analysis does not capture people who choose not to pursue care due to administrative hurdles or a lack of information. It also does not capture the many people who do not presently qualify for MaineCare and statefunded programs. The economic analysis does not account for workers who drop out of the labor force to provide care for loved ones with disabilities or behavioral health challenges. Direct care systems are complex and overlapping, but to meet the needs of Maine's people, the state should fully commit to improving data systems in partnership with direct care professionals and recipients, provider agencies, and advocates.

One potential solution is to authorize the Maine Health Data Organization (MHDO) to create a uniform reporting system on Maine's direct care gap. MHDO already analyzes claims data from all payers, which has the benefit of not limiting its analysis to MaineCare and state-funded programs. The offices of Aging and Disability Services and MaineCare Services could also regularly publish updates on the gap between the amount of supports and services approved and the amount people actually receive and could collect and publish data on staffing and wages by sector and geography. The new federal rule on access to Medicaid services includes reporting requirements, which could coincide with such efforts but should not delay progress at the state level.

Another issue which warrants further attention is the long-term health impacts and costs of failing to provide the supports and services people need. Those who are unable to access all the care they need, including people on waitlists who are not receiving any professional supports and services, are more likely to require more expensive acute health care and suffer negative health impacts. The state does not currently track health outcomes for people who are eligible for but not receiving supports and services, which precludes a fuller picture of the costs of the workforce challenges. Concerted efforts to collect this data could improve efforts to measure the costs and benefits of direct care policy interventions and the state should incorporate it into any future efforts to address this issue.

The case for bold action continues to build



In the same way that employers and policymakers recognize the importance of child care to the workforce, caregiving, especially unpaid care, must also gain greater consideration and support.

Last spring, MECEP reported on the high costs of Maine's care gap. Beyond the direct impacts on individuals who need services and care workers struggling with low-wages, the ripple effects are significant. Approximately 8,000 workers are out of the labor force tending to the care needs of an older family member. The absence of these workers from the workforce is costing Maine's economy close to \$1 billion in lost GDP and reducing state and federal revenues by as much as \$70 million.

While these costs are steep by themselves, they are only reflective of one year, with most of the data being gathered in 2022. 18 They also likely understate the true economic consequences since the analysis is based on people outside of the labor force who are caring for aging relatives — only one population served by direct care workers. Data is less available on people outside the labor force who care for loved ones with disabilities or behavioral health challenges and is excluded from the analysis of economic impact. As a result, the costs are likely greater than depicted here and will continue to add up over the years if we fail to address the care gap especially as more Mainers will require care and more workers

will be challenged to juggle caregiving responsibilities with the demands of their jobs.

This dynamic is highlighted by the most recent Maine State Plan on Aging Needs Assessment that includes results from a survey of informal caregivers; often family caregivers, who provide unpaid support that enables people to remain in their communities and delays placement in a nursing home. Of the informal caregivers surveyed, 59% are aged 64 years or younger. Thirty-nine percent of respondents work full time and more than half work full or part time. Among employed respondents, 65% reported going to work late, leaving work early, or taking time off during the day to provide care, while 17% of employed respondents had to leave a job altogether. Seventeen percent reported switching from full time to part time or otherwise cutting back their hours, while 9% took a leave of absence.

These responses are consistent with national studies on the toll informal caregiving takes on workers. In one analysis, 52.4% of employed caregivers reported their care responsibilities had interfered with their employment. Among caregivers who were not employed, 39.8% reported having quit or retired early due to caregiving demands.¹⁹

A 2019 report from Harvard Business School corroborates those trends. It found one-third of employees who left a position for caregiving responsibilities reported taking care of an elder with daily living needs as a reason for leaving their job, while one-quarter did so to care for an ill or disabled spouse, partner, or family member.

This study also found employers often do not fully appreciate the toll caregiving has on employees. More than 80% of employees with caregiving responsibilities admitted that caregiving affected their productivity. Thirty-three percent of respondents said caregiving affected their ability to perform their best at work all the time, another 14% reported an impact most of the time, and 36% sometimes. However, only 24% of employers responded that caregiving influenced workers' performance. While most employers know some workers will inevitably leave their jobs or move to part-time, very few measure how much this is caused by caregiving obligations.²⁰

AARP <u>estimated</u> that 166,000 people in Maine provided 155 million hours of unpaid care in 2021. A significant portion of these caregivers are presumably employed. Further research into the impacts of informal caregiving on overall worker productivity and labor force participation is warranted, but it appears to have a significant — and underappreciated

— impact on our economy. In the same way that employers and policymakers recognize the importance of child care to the workforce, caregiving, especially unpaid care, must also gain greater consideration and support.

Together we can close Maine's care gap



An all-hands-on-deck approach is needed, but for these efforts to succeed, the state must lead with bold policy.

Addressing direct care workforce challenges will require an all-hands-on-deck approach. Employers need to implement family-friendly policies that allow workers to juggle their work and family demands; municipalities and counties need to provide innovative solutions like adult day drop-in services; people in Maine must raise their awareness of the issue and volunteer in their communities. But for these efforts to succeed, the state must lead with bold policy that both honors the fundamental value of the people who need and provide these supports and recognizes why the economic case for investment is so important. Specific opportunities to pursue include:

Collaboration and engagement

 Expand membership of the Essential Support Workforce Advisory Committee to sufficiently represent the interests and perspectives of workers, clients, and other impacted groups

- Collaborate with high schools and institutions of higher education to create meaningful pathways for students to engage in this workforce
- Elevate direct care access and workforce issues in Maine's economic development priorities
- Prioritize culturally relevant recruitment and training pathways for New Mainer communities

Data collection

- Improve public data collection and reporting systems and engage stakeholders in data design
- Annually survey agencies and workers to measure job vacancies, turnover rates, and working conditions
- Engage Maine Health Data Organization to regularly measure the direct care gap for all payers
- Track and report health outcomes of people on waitlists or who are receiving a fraction of their approved care

Reimbursement, compensation, and innovation

- Raise reimbursement for the labor portion of direct care in all settings to at least 140% of the state minimum wage
- Ensure workforce investments are focused on improving long-term retention and include passthrough polices and clear guidelines to optimize worker benefit
- Prioritize timely reimbursements, including when rates change
- Create a universal worker training and credentialing system that provides workers portable and stackable credentials

- Fund innovation grants to help employers pilot programs to explore best practices for worker recruitment and retention
- Pursue innovative policies to provide benefits to direct care workers, including health, retirement, and education. Examples could include:
 - Create a state-subsidy for direct care workers to purchase insurance on the state's marketplace

- Create public higher education benefits for direct care workers and their immediate family members
- Explore direct care worker's access to the Maine Public Employee Retirement System

Conclusion: public and private support is necessary to fix this problem



Maine's direct care system is failing thousands of older adults, people with disabilities, and individuals with behavioral health challenges. This report finds more than 23,500 hours of approved home care for older adults go undelivered every week. Yet when accounting for data inadequacies and people who do not qualify for public programs, this figure certainly underestimates the true scale of the problem. While MECEP's 2023 report on direct care work identified the myriad economic costs of undervaluing direct care workers, this report aims to estimate the scale of the care gap Maine people face. To reduce the high rate of turnover and attract more than 2,300 more workers into direct care, MECEP recommends raising reimbursement to at least 140% of state minimum wage and exploring innovative ways to provide care workers health, retirement, and higher education benefits. Fundamentally, we urge state leaders to more deeply engage consumers and care providers in efforts to close our direct care gap.

In the words of workers: Emily



Emily has almost 30 years of experience as a certified residential medication aid (CRMA) and direct support professional (DSP), working with adults with developmental disabilities and in assisted living settings. We first spoke with Emily for our 2023 report, The High Cost of Undervaluing Direct Care Work. Since then, Emily has left the field of direct care. She now works as a medical receptionist in Portland. Emily is a member of the Direct Care and Support Professional Advisory Council.

The assisted living facility where I was working changed ownership last year. We stopped getting Christmas bonuses and extra vacation hours for perfect attendance. Raises that were scheduled before the sale were ignored. It felt like a kick in the teeth. About 90% of the staff left. There were very few days when I worked only eight hours, and I often couldn't take any kind of break because my wing was single staffed. There were so many days that I would leave in tears, feeling like I had failed my residents, because I was set up to fail. The system is just so broken. It feels like they will just use and

abuse us until we're all dried up and we're just husks. I was so invested in these people, and it makes me angry that I'm not doing that work anymore because it was just so untenable.

Low pay is the main reason we can't hire and retain workers in this field. People that are thinking about going into caregiving take one look at the pay and realize that they can go work at Five Guys or McDonalds or Dairy Queen and make as much if not more, and not have to worry about the stress and not have to worry about the overtime because somebody didn't show up and you can't leave.

There's also the cost of education and training. It can cost hundreds of dollars to get your 40-hour CRMA, and companies want you to have it before they hire you, even if you already have your 24-hour CRMA, DSP, and [Personal Support Specialist] PSS certification. They're all basically

The system is just so broken. It feels like they will just use and abuse us until we're all dried up and we're just husks. I was so invested in these people, and it makes me angry that I'm not doing that work anymore because it was just so untenable.

In the words of workers: Emily

the same thing, but they won't accept those in assisted living facilities. There's a lot of confusion with training and qualifications *that can deter* people from wanting to get into direct care.

Legislators should come and see what it's like for a single care worker to try to prioritize between helping the resident with explosive diarrhea and the resident sitting in her own urine and the resident who has fallen down and can't get himself back up. They should see what it's like when those things happen during meal time, when regulations require that worker to get all the trays delivered in just 20 minutes. Or when residents have wounds that need dressings changed three times a week, but the wound nurse authorized to change them only comes once a week. It would be nice if they could see what care workers go through and how they are put in impossible situations all the time.

I loved what I did. I hated the overtime and I hated the low pay, but I loved the job itself. I could go home at the end of every day knowing that I made someone's life a little better. I see this as a societal issue. Every job has value. How is it that this job of taking care of human beings and keeping them alive and happy and comfortable and clean has less value than almost every other job? As a society, we need to wake up and make a shift in our perceptions.



Emily stands at an intersection in Portland.

In the words of workers: Justin



Justin is a direct support professional, mental health rehabilitation technician, certified residential medical aid, and a qualified brain injury specialist with 20 years' experience. He currently provides care at several Kennebec county group homes for adults with brain injuries. Justin is a member of the Direct Care and Support Professional Advisory Council.

I've worked for several different agencies, and it feels like we're viewed as replaceable. They see us as glorified babysitters. No, I'm not a glorified babysitter. This job is hard, unforgiving, and affects every aspect of your life. Most of us feel like we are out there all by ourselves, doing a thankless job with no support.

I'm working longer, harder hours now, and so are my colleagues. We're getting burnt out. We're tired, but we stay because of loyalty to the people we provide care for. I've seen the low pay identified as a problem, but across the board I've seen very little effort to address it. It really irritates me. For what I make and the years I've been doing this, I should have walked away a while ago. There's no incentive for somebody to stay in this field when they can go into a different one and make more money, have better work-life balance, and get better benefits and supports.

Legislators could solve many of the problems in direct care by offering free training through the technical colleges that can build towards a four-year university degree. First, develop a core curriculum that covers all the common subject matter in the different care giver certifications and give it a college credit. Then, for every year of service care workers provide, they should get two or three free classes towards a degree in psychology, mental health, or social work. College is expensive. But if your work can earn a base of credits that can be applied to a four-year degree at a university, that's a real incentive. That will attract people. And it will also save companies money on all the training. The money they save could be put towards wages and benefits, instead. When

I would invite any lawmaker or the governor to come tour any of these facilities. I want them to know that these people aren't numbers. They're real people and they need help.

In the words of workers: Justin

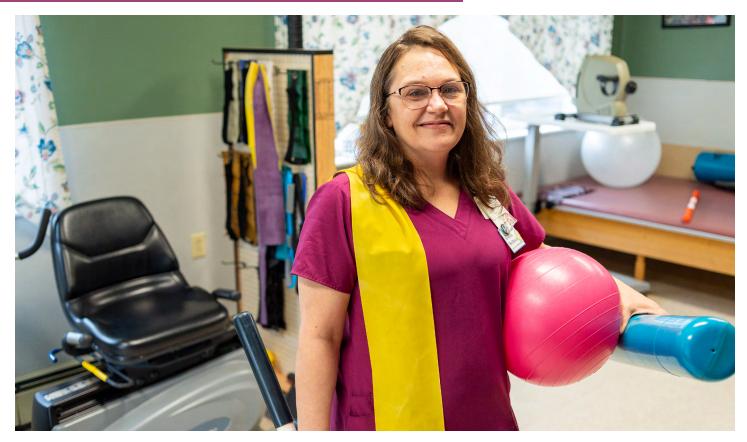
wages and benefits increase, they're more likely to retain those workers once they've completed their four-year degree.

I would invite any lawmaker or the governor to come tour any of these facilities. I want them to know that these people aren't numbers. They're real people and they need help. There are a lot of great companies out there that just need more funding to keep things going. I mean, I get it, taxes will go up. But I would pay higher taxes to help these people. I would. We are all one step away from a residential home, a nursing home, or a hospice house. Who would you want to be there, taking care of you?



Justin stands in front of the Maine State House, holding a cup of coffee.

In the words of workers: Mechelle



Mechelle is a certified nursing assistant (CNA) with 28 years of experience working in home health care, assisted living, and residential care for people with intellectual and developmental disabilities. She currently works as a restorative nurse aid at a nursing home in Presque Isle. Shortly after sharing her story for this report, Mechelle learned that the nursing home where she works is preparing to close permanently. Mechelle is a member of the Direct Care and Support Professional Advisory Council.

When we don't have enough staff, we really rely on the staff we do have. When someone calls out sick, it makes us even shorter. We get called in on our day off. I find myself agreeing to shifts that I really don't have the energy to do. I'm making myself even more tired, more worn out, and after a few weeks of that I end up missing a couple of days of work myself, because now I've made myself sick. It's a vicious cycle. I've seen a lot of good CNAs leave the field altogether because they're just completely burnt out. They just didn't have any more in them.

When I started working here four years ago, I made \$14.75 per hour. After a couple of years, I made almost \$4 in raises. I was making \$18 when the base rate was changed to \$20 during the pandemic. On paper it was a wage boost, but in reality, it was a wage cut, because it didn't factor in all my years of raises and experience. I've been a CNA for nine years, but now I'm getting paid the same as someone who's been a CNA for nine days. That's really frustrating. It makes me feel like all the experience I have doesn't mean anything. The skills I bring to the table are lessened because it's reflected in how I'm paid. It doesn't feel fair.

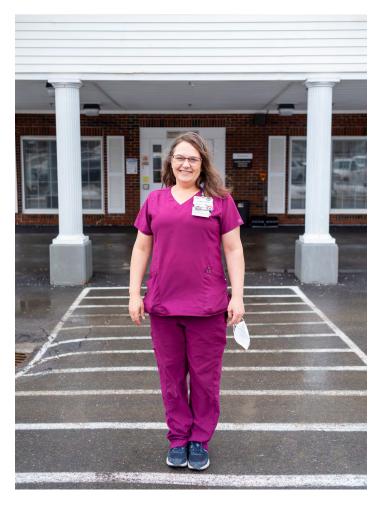
I'm lucky enough to have health insurance and a 401K. We can get meal tickets here. But what would really help a lot of people is having child care. Staff members with kids set their schedules so that their At some point in their life, every single person is going to need someone like me. I don't think that a person who has this important of a job should have to stand in line at the food pantry... I know I matter. I know I make a difference.

In the words of workers: Mechelle

shift ends in time to pick their kids up from school. But if the person scheduled to follow that shift calls in sick, the staff member can't leave. They're stuck there. They're obligated. If they leave, that's abandonment. So that leads to frantic phone calls, "Can you go get my kids?" They're stressed, they're crying, "What am I going to do?!"

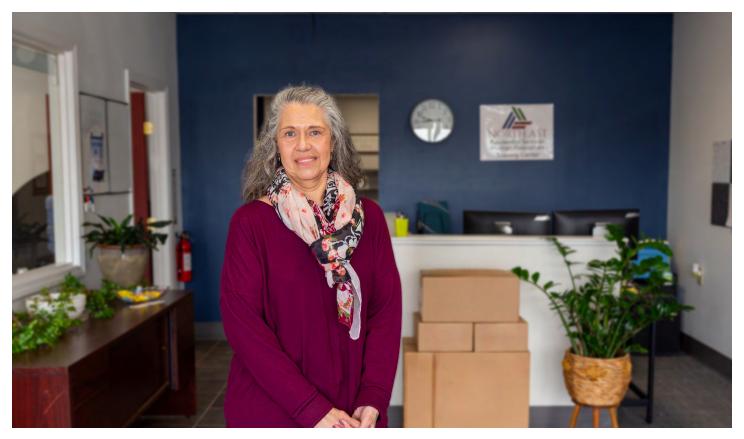
There really needs to be some kind of fail safe for situations like that. Because for parents with young children, sometimes it just takes one experience like that to convince them to find a new job.

I don't think lawmakers really understand the value and importance of this role in people's lives. At some point in their life, every single person is going to need someone like me. I don't think that a person who has this important of a job should have to stand in line at the food pantry. I don't think we should be struggling, trying to figure out if we're going to pay our electricity bill or get groceries. I know I matter. I know I make a difference. And that's OK, but I would not mind my wallet to be padded a little. It sure would make my life a lot easier.



Mechelle stands in front of her workplace, holding a face mask at her side.

In the words of workers: Stephanie



Stephanie has worked in the field of developmental disabilities, intellectual disabilities, and autism for 31 years. She has worked in day programs and residential care facilities, and now trains other direct support professionals. Stephanie is a member of the Direct Care and Support Professional Advisory Council.

For my first eight years as a direct support professional, I worked two full-time jobs with very little time off. That's how we had to do things because that's how I had to pay my bills. I loved what I was doing. I still do. But it impacted my personal life terribly. It's the same for the people that I'm training now. They often have two or three jobs because the pay is so poor. Without that good pay, people aren't going to stay. They're going to leave for a better paying job.

I see people in similar roles in other fields making far more than I do. My sister is a physical therapist in a hospital, and she makes \$52,000 more than I do. My other sister is a teacher, and she makes \$30,000 more. I think that shows an undervaluing of the people we support, not just an undervaluing

of those providing the support. We are looking after your mother and your grandmother. What do you think your mother and your grandmother are worth?

To attract and keep workers, we need to be looking at the cost of living. We have to take that into account when we determine what is a reasonable wage. Once people are in the door, keeping them involves making people feel valued, and recognizing what they do. It's providing support with child care and health insurance, and making sure people can take care of themselves so that they can provide the best care for others. If we can see progress on wages, benefits, and respect, I think it will draw in more people who will come in and stay. Because people could sustain their life, and people stay in jobs that sustain their life.

When you work with individuals with disabilities, you see the impact in their quality of life... A person with a disability is always going to have that disability. But they could be healthier because they're happier. And that's what a good care team can do.

In the words of workers: Stephanie

When you work with individuals with disabilities, you see the impact in their quality of life. People who don't have good caretakers tend to have more health issues. They tend to have more interfering behavior issues, where they spend more time trying to get their needs met than they do just living a good, happy life. People who have good caretakers are happy. They're going out and doing things. They're healthier. A person with a disability is always going to have that disability. But they could be healthier because they're happier. And that's what a good care team can do.

My mom also worked in this field, and when I started she tried to talk me out of it. She told me I'd never make a livable wage because she also had a hard time doing it. But most of the people who get into this line of work aren't doing it for the money. We do it because we want to care for people who can't care for themselves.

That's why I still do it, and that's why I thank people who are still here doing this devalued job. Because if they weren't here, the people they support wouldn't have the care they need.



Stephanie speaks in front of a group, leading a training for other direct support professionals.

In the words of workers: a.m.k



a.m.k worked in hospitality before moving in with her 86-year-old mother and taking on her full-time care. Since taking on that role four years ago, a.m.k received certification as a personal support specialist, qualifying her to receive some compensation for the care she provides.

I was told there might be a 30 or 60 day wait before my mother would get to the top of the waiting list for home and community-based services. Even though mom qualified for the program, and I was living with her and providing the care, it took over a year before I got paid as a caregiver. Thank goodness for the pandemic unemployment money. We never would have survived on just her income. There were so many out-of-pocket expenses beyond food and rent. My mom could no longer drive, so I had to get a car. I now have 12,000 miles on my car and all but about 50 came from taking my mom somewhere. I wonder how much I would have been reimbursed for that if transportation was a covered expense?

I was asked how I spend my time as a caregiver. There are at least 25 regular tasks that are a part of managing my mom's life. Some are financial, some are medical, some are housing-based, and many are related to personal care, hygiene, and physical therapy. I'm doing the job of the entire staff of a nursing home. I work 24 hours a day, seven days a week, providing care and being available for anything that happens in the middle of the night or during the day. I get paid for 24 hours per week.

When you think about a nursing home – the number of employees, the property, the maintenance, the human resources, the paperwork, the oversight – and then you think about home-based care, with one person doing all of that, I would say I deserve more. I'm managing my own long term care facility right here. I've worked just over 1,300 days as a full-time caregiver over the last four years. That's about a quarter

Long-term care is anywhere, and we are the front line. Pay us. Pay us for every hour we work. We shouldn't have to leave the workforce to take care of a loved one. We should be able to switch jobs to provide that care if we want to. It should be an option.

In the words of workers: a.m.k

of a million dollars in lost wages if I were paid for every hour I worked at my current wage.

I've barely contributed to social security in the four years I've been a caregiver. I don't have retirement savings. There are 53 million unpaid caregivers. Guess who's going to be needing the safety net because they weren't paid for the 5, 10, or 15 years they cared for a loved one? It's all going to cost more in the long run.

If we were provided incentives, training and support, if we got rid of the red tape, and were paid a fair wage for every hour worked, it would reduce costs. We'd be able to pay market rate for an apartment or even buy a house, freeing up subsidized housing for others who really need it. Making this job a viable choice for family members would reduce over-stays in hospitals and the stress on long-term care facilities. We'd be able to contribute more to Social Security and save for retirement. We'd also spend a lot more money in our community.

Long-term care is anywhere, and we are the front line. Pay us. Pay us for every hour we work.

We shouldn't have to leave the workforce to take care of a loved one. We should be able to switch jobs to provide that care if we want to. It should be an option.



a.m.k shares a moment with her mother, who sits smiling in the car a.m.k bought to transport her to appointments.

Notes

- 1 Maine Department of Health and Human Services, Office of Aging and Disability Services, <u>"Efforts and Progress on Implementing the Recommendations of the Commission to Study Long-term Care Workforce Issues,"</u> February 2024.
- 2 Section 21, services for people with intellectual disabilities and autism spectrum disorder; Section 63, in-home and community support services; Section 69, independent support services; Section 96, nursing and personal care services.
- 3 Data from the 2022 was from November, whereas data for 2023 was from December.
- 4 Available by request.
- **5** Presentation of the Director of the Office of Aging and Disability Services to the Essential Care Workforce Advisory Committee, May 13, 2024.
- **6** MACSP IDD Care Gap Service Needs Survey was completed by 25 organizations serving 1,729 of an estimated 6,037 total statewide population of unduplicated individuals across Sections 18, 20, 21, 29, 50, 97-F services.
- 7 Maine Department of Health and Human Services, Office of Aging and Disability Services, HCBS Access Measures.
- 8 Maine Department of Labor, Center for Workforce Research and Information, Direct Support Worker Market Analysis, Presented to the Joint Standing Committee on Health and Human Services.
- 9 Maine State Plan on Aging Needs Assessment, Final Report, January 2024.
- **10** Maine Department of Labor, Center for Workforce Research and Information, Direct Support Worker Market Analysis, Presented to the Joint Standing Committee on Health and Human Services.
- 11 PHI, Direct Care Workforce State Index, Maine.
- 12 Estimate in 2023 dollars. Sources include, Dorie Seavey, "The Cost of Frontline Turnover in Long-Term Care," Better Jobs Better Care, October 2004; Kate Bahn and Carmen Sanchez Cumming, "Improving U.S. labor standards and the quality of jobs to reduce the costs of employee turnover to U.S. companies," Washington Center for Equitable Growth, December 2000.
- 13 These entry-level requirements include usually requiring some previous work-related skill, knowledge, or experience; usually requiring a high school diploma; and often involve using knowledge and skills to help others. More information can be found at the O*Net Job Zone Reference
- 14 PHI analyzed Bureau of Labor Statistics (BLS) Occupational Employment and Wage Statistics (OEWS) May 2022 State Occupational Employment and Wage Estimates and the O*NET 28.0 Database
- **15** Bureau of Labor Statistics (BLS) <u>State Occupational Employment and Wage Statistics (OEWS)</u> May 2023. These figures likely do not include the value of recruitment and retention bonuses provided by ARPA funds, according to definitions of OEWS data.
- **16** Office of Aging and Disability Services provided data to MECEP from the 2022 HCBS recruitment and retention bonus program reports.
- **17** According to data provided to MECEP, agencies reported a total of 266 workers received bonuses that were not identified as retention or recruitment bonuses.
- 18 Based on survey data collected from January 2022 through April 2024, there was an average of between 6,100 and 9,500 adults outside of the labor force due to elder care responsibilities. The estimated lost gross domestic product for Maine is between \$844 million and \$1.3 billion per year. As more of our population ages and needs care, it is likely the number of adults outside the labor force will increase over time.
- **19** Margaret L. Longacre, Vivian G. Valdmanis, Elizabeth A. Handorf, Carolyn Y. Fang, Work Impact and Emotional Stress Among Informal Caregivers for Older Adults, <u>The Journals of Gerontology: Series B</u>, Volume 72, Issue 3, 1 May 2017, Pages 522–531.
- **20** Joseph B. Fuller and Manjari Raman, <u>The Caring Company</u>, <u>How Employers Can Help Employees Manage Their Caregiving Responsibilities</u> (Cambridge, MA: Harvard Business School, January 2019).

For links, visit mecep.org/directcare-2

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Members of the Essential Support Workforce Advisory Committee

Leadership and staff of the Office on Aging and Disability Services and the Center for Workforce Research and Information

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About Maine Center for Economic Policy

Maine Center for Economic Policy (MECEP) is a nonprofit research and policy organization dedicated to economic justice and shared prosperity by improving the well-being of Mainers with low and moderate income. Since its founding in 1994, MECEP has provided policymakers, advocates, media organizations, and the public with credible, rigorous research and analysis. MECEP is an independent, nonpartisan organization.

About the author

Arthur Phillips, MECEP Economic Policy Analyst works on MECEP's inclusive economy portfolio and leads outreach and advocacy on labor issues. Arthur worked for seven years as a researcher and campaign strategist with the hospitality workers' union UNITE HERE. Before that, he conducted research published by the Economic Policy Institute and the Center for Economic and Policy Research in Washington, DC. He holds a bachelor's degree in history with a minor in economics from McGill University.