EXECUTIVE SUMMARY

Illinois will experience an unprecedented demand for care services for older adults and those requiring long-term care as the state's aging population grows in the coming decades. Direct care workers are a driving force in ensuring that older adults and those requiring long-term care receive medical and non-medical services. These home health aides, certified nursing assistants, and personal care aides provide flexible care in homes and personal living settings that combine independence, comfort, and professionalism. If Illinois seeks to equitably and responsibly expand its direct care workforce, the state of Illinois should lead in charting a path towards meaningful worker protections and career advancement opportunities.

Direct care is an integral part of long-term care. As a part of the healthcare continuum from hospital to home, direct care workers will be an anchor in Illinois’s strategy for responding to the shifting care demands of the next decades. However, direct care workers today are at the mercy of a turbulent gig economy and the outdated understanding of their workforce potential. Direct care workers are asked to provide critical medical and non-medical care needs in the most intimate care settings, but still face poverty wages, confusing training standards, and stagnant career ladders. Worker recruitment and retention should be top priorities for meeting Illinois’s goal of creating 35,000 new direct care jobs by 2022, and reforming the state training standards and pathways can create tangible career incentives and fairer working standards for current and future direct care workers.
More specifically, Illinois can lead this change through four initiatives:

1. Standardizing training curriculum and updating certification requirements;
2. Authorizing more advanced direct care roles with incentives for further training and higher pay;
3. Creating formal pathways for more advanced direct care roles, transferable hours, and experience into allied healthcare careers; and
4. Investment in a statewide training and career development fund that is responsive to changing direct care needs.

By advocating for the economic security of its direct care workers, Illinois can take steps to ensure the well-being of those requiring care and those providing it. Using the following policy framework, the direct care industry can begin a revitalization that will both seek to professionalize direct care roles and create accessible economic ladders for workers. The first half of this paper (sections I, II, and III) provides background and context for the nature of direct care work, the profile of the workforce, and current problems facing workers. The second half (sections IV and V) introduces past examples of how private and state actors have addressed training and workforce development, the motivation behind these efforts, and their key takeaways. These insights ultimately inform the prescribed policy changes in the final section, and how they can be implemented in Illinois.

INTRODUCTION

Direct care workers such as home health aides, personal caretakers, and nursing assistants provide a vital intersection between long-term care and personal comfort that allows flexibility and independence at home for the elderly and those with disabilities who require assistance (Buhler-Wilkerson 2007). Their intimate and professional care plays a vital role in providing clients with a comfortable quality of life while working to identify and prevent more serious health problems from occurring (Coleman et al. 2006). While customers consider many factors when deciding to utilize direct care, such as independence and safety, it also tends to be less costly than more traditional care environments such as nursing homes or assisted living facilities. In America today, there are more than 4.4 million direct care workers who cover an estimated 70 to 80 percent of all daily
interactions with the elderly (PHI 2011). As direct care workers are entrusted with the care of individuals who may be immobilized and who require specific lifestyle adjustments or monitored care, they also provide companionship and emotional support during often turbulent times in a client’s life.

Illinois will face an unprecedented demand in taking care of its elderly populations and people with disabilities in the coming decade. The adult population over 65 in Illinois is estimated to jump from 1.9 million to 2.5 million between 2015 and 2025 (PHI 2016). The number of adults over 85 will increase from 254,000 to 279,000. In response to this population shift, Illinois must promote a robust and respected direct care workforce at the center of its long-term care strategy. Even though projections indicated an inflow of 17,860 new workers from 2015 to 2025 (PHI 2016), it is estimated that by 2022 Illinois will need over 35,000 more direct care workers (Kalipeni et al. 2018), thus creating a serious labor shortage in that area.

The lack of dedicated state recruitment and retention policies exacerbates the need for workers, as the focus on job quality and working conditions becomes more relevant. There are notable difficulties in attracting and retaining direct care workers because these roles have traditionally yielded low pay, sparse benefits, and challenging hours (PHI 2016) (Kalipeni et al. 201*). Unfortunately, high employee turnover is also extremely common (Espinoza 2018). Direct care work is seen both as “priceless labor”—as it is of critical importance to families and the vulnerable in our society—and as work lacking “true transferable skills.” As direct care work rarely creates documentable caretaking portfolios, profit generation, or consumer goods, workers face challenges in demonstrating concrete—and easily understandable—results from their efforts. Documented “hard and soft skills” are often difficult to certify, and many times the tasks demanded are straining and require on-the-job flexibilities that go unrewarded (Scales 2017). Due to varying standards for obtaining credentials through training, direct care roles are subject to labor market vulnerabilities, as workers cannot monetize or reference previous experiences and skills built in private spheres of the living space. Direct care workers are also called upon to navigate complex family situations, disentangle constant emotional burdens, and adapt to intimate but professional standards in the privacy of a person’s home or living space. Such demands muddle employer boundaries of professionalism while disempowering workers in their ability to negotiate for better working conditions (Leberstein, Tung, and Connolly 2015). Workers often face limited training for constantly evolving care situations, which can lead to avoidable hospitalizations, lawsuits, and employee turnover. The lack
of federal training standards and inconsistent state standards are not reassuring pillars that families and workers can rely on (Institute of Medicine 2008).

Healthcare workers navigate complex care environments. Their work is meaningful and rewarding because it provides independence and comfort to older adults or people living with disabilities who require assistance. How we equip direct care workers is at the critical intersection of how the United States healthcare system will respond to our population shift in the next decades. This white paper will explore the potential for an integrated training and certification system that hopes to benefit direct care workers, employers, and consumers in Illinois.

**BACKGROUND**

In Illinois, home health aides, nursing assistants, and personal care assistants are collectively known as direct care workers. Through integration into almost all levels of long-term health care delivery, their tasks are vital in continuing care and maintaining quality of life for elderly adults and people with disabilities who require assistance. (PHI 2011). Here, we will discuss specific roles in direct care, the lives of workers, and the policy actors that shape working conditions.

**Roles, Training, and Skills**

When describing long-term care roles, there are differing care settings including the home, assisted living facilities, nursing homes, and hospitals. While more skilled care needs such as late-stage dementia care and hospice require dedicated facilities, some clinical tasks (such as blood pressure and glucose monitoring, or range of motion movements) can be carried out in the comfort of one’s own home or care environment. These paraprofessional roles revolve around clinical tasks that focus on preventative medicine and chronic disease vigilance. Equally important, non-clinical tasks in direct care focus on activities of daily living (ADLs) such as eating, dressing, and bathing. Listed below are general job descriptions from the Paraprofessional Healthcare Institute (PHI), a national long-term care and disability services research and advocacy group.
<table>
<thead>
<tr>
<th>Role and Skill</th>
<th>Training/Certification Requirements in IL</th>
<th>Average Hourly Pay</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certified Nursing Assistant (CNA)</td>
<td>Nursing Assistants or Nursing Aides generally work in nursing homes, although some work in assisted living facilities, other community-based settings, or hospitals. They assist residents with activities of daily living (ADLS) such as eating, dressing, bathing, and toileting. They also perform clinical tasks. 120 Hours of Training 40 Clinical Education Hours State Certification Test Background Check</td>
<td>$14.31</td>
</tr>
<tr>
<td>Home Health Aide (HHA)</td>
<td>Home health aides provide essentially the same care and services as nursing assistants, but they assist people in their homes or in community settings under the supervision of a nurse or therapist. They may also perform light housekeeping tasks such as preparing food or changing linens. Same requirements as CNA</td>
<td>$12.71</td>
</tr>
<tr>
<td>Personal Care Assistant (PCA)</td>
<td>Personal Care Assistants work in either private or group homes. They have many titles, including personal care attendant, home care worker, homemaker, and direct support professional (the latter work with people with intellectual and developmental disabilities). In addition to providing assistance with ADLS, these aides often help with housekeeping chores, meal preparation, and medication management. They also help individuals go to work and remain engaged in their communities. Their tasks are non-medical. Employer training usually provided</td>
<td>$12.71</td>
</tr>
<tr>
<td>Informal Caregiver</td>
<td>Informal caregiver roles vary in a number of medical and non-medical tasks. The labor performed is often paid informally through under-the-table work or is unpaid, in the case of family caregiving. Often untrained, though there are state-approved resource guides</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Note: The term “home care” commonly refers to Home Health Aides and Personal Care Assistants, and is used interchangeably with direct care. Average Salaries are based off of May 2019 BLS Occupational Employment Statistics median wage per hour.
Worker Socioeconomic Status, Demographic Information, and Labor Conditions

Illinois’s home care workforce is disproportionately racialized and gendered in comparison with related health professions: nine out of ten home care workers are women, and people of color represent more than half of direct care workers. The median age of direct care workers is 46 (PHI 2016).

Stressful working conditions that are thought to create adverse working hazards are unfortunately common in this industry. In one study surveying Medicare-certified Home care aides in Chicago, interviewees described common stressors including workplace abuse, lack of training, and lack of information in the care environment. When surveyed for health indicators, direct care workers in Chicago reported elevated rates of stress-related health conditions such as hypertension, asthma, and arthritis. Smoking habits of direct care workers were double those of the average American, and mental health issues were a common theme among interviewed direct care workers (Muramatsu et al. 2019).
The average home health worker in Illinois makes less than the median state worker, as average salaries have failed to grow with inflation ($10.57 per hour in 2005, $10.59 in 2015, and $12.25 in 2019) (Campbell 2019). These wages are among the lowest in the long-term care industry and have historically been at the lowest end of healthcare pay (PHI 2016). Making a consistent income has been a difficult prospect for direct care workers in Illinois, especially with more than 70 percent of workers working part time or only during parts of the year. This is thought to be due to traditionally erratic and irregular scheduling in direct care jobs. Current socioeconomic trends amongst home care workers are troubling, most notably showing that home care workers make on average $12,600 per year ($11,200 below the projected cost of living of a single adult), as well as showing that more than 26 percent of the home care workforce is below the federal poverty line (compared to the 7 percent average in Illinois) (PHI 2016).

The realities of “gig work”—the breakdown of traditional employment relationships in favor of transient contract work—have reached this industry, as direct care workers are increasingly labelled as independent contractors (Leberstein, Tung, and Connolly 2015). The contractor label allows agencies to forgo employee benefits, workplace supports, and competitive wages for workers. In addition, Illinois has grappled with the “gray market,” in which individuals are hired outside of formal labor arrangements. These personal agreements are usually unregulated and unscreened, giving long-term care employers and families the ability to pay lower-than-market wages. Intra-family caregivers, such as children of parents needing long-term care, are frequently unpaid or not formally trained (Levine and Murray 2004). According to the Illinois Department on Aging, one in four households have older family members who require care, while an estimated 85 percent of long-term care services are provided by unpaid caregivers. Estimates on the total lost wages of unpaid caregivers range from $45 to $95 billion per year (IDOA 2017). While Illinois does provide days for respite and support for family caretakers, it does not provide pathways for such caregivers to capitalize economically on their valuable learned experiences and labor.

Current State of Labor Organizing and Regulation in Illinois

Direct care employment can be organized in different ways. Most direct care workers in Illinois are employed through registered and certified businesses known as agencies. State-run programs often directly employ workers or contract with agencies. As a result, an estimated 73 percent of all direct care workers are
employed by the state. Independent providers—directly employed by clients or families—also make up a sizable portion (17 percent) of the workforce (IDOA 2017). Illinois’s largest representative of organized direct care workers is Service Employees International Union Healthcare Illinois and Indiana (SEIU HCII), representing more than 50,000 direct care workers (SEIU HC 2020). Illinois has maintained strong labor representation and does not currently have union-crippling “right-to-work” laws. Lastly, Illinois’s Department of Public Health is the main regulatory body in issuing certifications for employers to conduct business and for workers to legally practice. The Department of Public Health does not set uniform training standards when certifying direct care workers, relying instead on Medicaid and Medicare certification standards and other disparate industry standards as benchmarks for worker education.

THE PROBLEM

Low Retention and High Turnover Rates Hurt Workers, Employers, and Consumers

High turnover rates can be a symptom of difficult working conditions and lack of training (Gorman 2015), but are also their own problem as employers lose out on potential gains and employees are faced with the inability to accrue gained work experience and income. Worker turnover in the direct care industry in Illinois has echoed national data, which ranges from 25 to over 100 percent per year (Banijamali, Hagopian, and Jacoby 2012). The Health and Medicine Policy Research Group estimates that home care workforce turnover rates in Illinois range from 40 to 65 percent, while some regions of Illinois reported that nearly 72 percent of workers left their jobs after a year (PHI 2016) (HMPRG 2015).

If an estimated 35,000 additional direct care workers need to be trained to keep pace with the demand for workers by 2022, high turnover rates within the industry will only exacerbate the workforce shortage, while continuing to fuel cycles of problematic transient contract work for those in the field. Consumers face issues with frequent turnover as well. Quality of care can suffer as a result of frequent new staff training and the inability to build client-provider relationships. A motivated, respected, and well-equipped workforce will bring out the best quality of care for Illinois’s elderly and those with disabilities. Illinois should seek to address the underlying factors of high turnover and low retention rates described below (Castle et al. 2019).
Complex and Confusing Regulatory Standards for Workers and Employers
Blur Official Recommended Practices

Illinois has a fractured training and certification system for direct care workers that confuses employers, workers, and consumers alike. To be employed with a Medicare-Medicaid certified home care agency as a home health aide in Illinois, workers must first achieve the skills designation of an Illinois certified nursing assistant (CNA). Workers looking to be certified must complete a minimum of 120 hours of training, with 40 of those hours in clinical settings, and pass a written competency test (Ill Admin Code 2019). Personal Care Aides and other non-medical positions such as caregivers often require even fewer hours of training, which are often done online. Programs offering training often do not subscribe to state or federal training curriculum standards, but are still vetted under the Department of Public Health for board approval. As differing curricula are put forth into many accredited programs, workers face non-uniform training regimens that create skill differences across the industry.

In addition, the lack of a uniform state curriculum has created challenges in swiftly responding to changes in direct care best practices. A Chicago Tribune article in 2019 described the inadequacy in training for specialized care conditions including dementia and Alzheimer's. While the state has signed a law mandating eight hours of training for workers who will care for those living with Alzheimer’s disease and dementia (Ill Admin Code 2019), it is unclear whether the law’s mandated training provides sufficient content and time to produce significant results. As dementia and Alzheimer's are not the only major conditions seen in the direct care industry, interviewed experts questioned the efficacy and authenticity of the specialized additional training from private agencies, commenting that the use of “care specialization” was a “branding and marketing decision” rather than one backed by care efficacy (Schencker 2019).

As the population requiring direct care grows in the next decade, so will the need for more diverse and specialized curricula that includes topics such as trauma-informed care, HIV and AIDS training, language skills, and cultural competency training. With no uniform and accredited state training curriculum and standards, consumers face serious information asymmetry when choosing care for themselves or loved ones. Workers also lose out on ascertaining vetted best practices for developing skills in their careers.
Lack of Clear and Viable Career Outlook and Proportional Compensation Lead to a Stagnant and Unmotivated Workforce

Turnover is often closely tied to worker engagement, satisfaction, and motivation (Yeatts et al. 2010) (Jant et al. 2016). Workers in this industry lack certifiable training that is transferable to other professions, such as certification that would be provided by professional schools and formal academic environments. Additionally, there is no enforceable increase in pay or officially recognized experience given after receiving and applying such training. This is due, once again, to the nebulous standards offered by the state and the lack of transparency in training programs set up by employers and industry associations. As a result, employers may not have an incentive to fund further training or specializations for high risk care situations, and workers may not find extra training worthwhile if no added economic incentives are present. While constant training and engagement allow workers to gain insight and skills that aid in perfecting their roles, there are no robust economic or career development gains in pursuing these activities.

Lack of Transparency and Hidden Costs in Contracts Lead to a Disillusioned Workforce

Independent home care agencies and nurse staffing agencies commonly contract with nursing homes, independent households, or subcontracting placement agencies. Throughout the process, direct care workers are further removed from their employers' support and direct contact due often to multiple layers of job coordination.

Misrepresentation of contracts is related to training and preparedness, and is also a serious concern that often goes unreported. In these situations, employers often ask direct care workers to perform tasks outside of their medical skillset or their physical capacities. This is due to inaccuracies in the work description workers receive prior to entering the client's home. For example, direct care workers may not be notified about potential mental illness or heavy immobility of a client until their shift begins. As a result, these unspecified added tasks put both the direct care worker and the consumer at serious legal and health risks. This practice also places both the patient and provider in an uncomfortable and dangerous position, in many cases resulting in the worker being pressured into performing tasks that they are not equipped for out of fear of retaliation. Because worker and client
risk assessments are not mandated by the state, a legal framework for workers pursuing legal action against the aforementioned unfair contracts is difficult to find.

POLICY OPTIONS AND CASE STUDIES

Employee Training and Evolving Care Models in Direct Care

Like other allied healthcare fields, direct care employers have many reasons to develop continuous training and co-learning objectives for their employees and themselves. For one, training has repeatedly been shown to lead to high levels of worker satisfaction and low levels of attrition, key factors in creating a strong, motivated workforce (DHHS 2015) (Lerner et al. 2010). As the health service industry shifts toward expanding the care environment from the hospital and nursing facilities to the home or via telemedicine, direct care agencies and unions are tasked with providing their own training regimens, lacking guidance from federal- and state-level standards. While employers are direct stakeholders in shaping training and industry standards, states are ultimately in an opportune position to shape training standards to be more evidence-based and responsive to the changing care industry.

Several states, such as New York and Washington, have implemented widespread, state-level reforms that have shaped the training standards and pathways for employees in the field. The following case studies offer insight into successful strategies and shortfalls.

Multi-Employer Joint Benefit Funds in Education

Different training partnerships have been established between employers and organized labor, operating through a special jointly managed organization governed by both management and labor representatives. Commonly carried out by a Taft-Hartley Multiemployer Fund, a board of trustees from both parties serves to administer functions of the fund and implement changes directed by the stakeholders in the form of a nonprofit organization. These benefit funds can provide direct education services independently or contract with other providers if existing infrastructure is deemed more effective.
Case Studies

Service Employees International Union Healthcare Northwest Training Partnership

Throughout the 1990s and early 2000s, Washington State looked to invest more public funds towards home-based long-term care in response to growing costs and consumer demand for in-home services. An estimated 77,000 new personal care aide jobs will be needed for Washington between 2012 and 2030 (Choitz et al. 2015), and so significant job training efforts will be required. Washington's approach for scaling up the training Program for more individuals can serve as a model for other states.

In 2006, the Service Employees International Union (SEIU) chapter 775 established the “Training Partnership” between a wide array of public and private agencies and SEIU 775. The Training Partnership operated as a statewide nonprofit Taft-Hartley fund, providing training and career development resources for unionized direct care employees. As a multiemployer fund, participating agencies and the union jointly contributed and operated on a shared, collective training standard. There is equal representation of labor and agency management on the board of trustees of the nonprofit governing the fund, while funding for the program was settled through collective bargaining agreements.

The Training Partnership offers 75 hours of basic training online and in person to ultimately prepare trainees for a certification exam by the Washington State Department of Health. When completed, most wages for unionized employees increased by .25 cents per hour. After basic training, the program offers advanced training options that give trainees pathways into apprenticeship programs and management training, as well as career pathways into allied health careers. While the most recent contextualized data is from 2015, the Training Partnership saw roughly 7,000 home care aides obtain certifications in the first three years of the program with basic training requirements completed at a 93 percent rate, and Continuing Education course options (apprenticeship, management training, further training) completed by 95 percent of all who enrolled in the course.

The Training Partnership's successes are mainly due to its stakeholders' ability to pursue long-term initiatives to benefit the industry. Most notably, SEIU and other advocates were able to overwhelmingly pass two statewide voter ballot initiatives to increase state training and certification standards (Ballotpedia 2020). The Training Partnership first created a widespread consensus curriculum under its
training fund with industry and labor stakeholders, then proceeded to push the state's official training standards to be up to par with the Training Partnership. In addition, the Training Partnership addressed job stagnation that often led to increased turnover by providing advanced educational pathways as well as increased wages, albeit at a small rate, for successful training completion. While evaluation of impact and outcomes continues today, the Training Program's model presents key insights on the convergence of both regulatory standards and viable career pathways.

New York Advanced Home Health Aide Law

In 2016, New York State created the job category of Advanced Home Health Aide (AHHA) in an effort to expand home care workers' skillset to encompass more advanced tasks. With additional training and certification, state-certified home health aides are allowed to provide services such as administering routine medications and certain bodily injections. Commonly performed by Licensed Practical Nurses (LPNs) in formal care settings (nursing homes, assisted-living facilities, hospitals), the tasks authorized to AHHAs allow for a greater range of care for those living at home (NY Code). The 2015 AHHA Advisory workgroup describes the role of the AHHA as being to:

Provide crucial support to family caregivers by allowing paid aides to provide services for which they are currently responsible. It also will offer additional opportunities for career advancement for home health aides and provide flexibility to health care providers that serve individuals in the community, potentially increasing the availability of the home and community based services workforce. In addition, the proposal will promote safety by providing that such tasks are carried out by individuals with training and under supervision (NY Department of Health 2015).

As the next step in career development for home health aides (HHAs), current HHAs are able to enroll in the State Education Department (SED) approved AHHA Training Programs through employer-based, union-based, or independent training programs. After 125 hours of supervised classroom and clinical practice, candidates must pass the New York Medication Aide Certification Examination (MACE) to be listed as an AHHA in the New York Health Worker Registry (Pearson Vue 2019).
Unlike the SEIU 775 Training Partnership’s initiative to raise overall state certification standards, New York lawmakers identified specific gaps in home care services that could be filled through AHHA roles rather than system-wide changes. The law’s transient nature is one of its strengths, as the legal authorization of AHHA is set to expire on March 31, 2023. Based on a mandated program evaluation on October 1, 2022, lawmakers will be able to better respond to changing care needs that direct care workers will face in the future by optimizing current care roles for workers and consumers (NY Legal Code). In future changes to the AHHA role, New York lawmakers must address certain shortcomings and missed opportunities in the law. For example, the AHHA training programs and certifications cannot fulfill academic requirements for a participant to become an LPN, even though the roles of AHHAs are directly derived from LPN roles. As a result, AHHA training programs fail to produce academically recognized transferable skills in higher skilled health professions, potentially capping career development pathways in direct care unnecessarily. Lastly, it is yet to be seen if the AHHA position will yield substantially higher pay for those who undergo the training. Industry actors and government regulators should be cautious of roles that require more training but are not fairly compensated as a result.

When looking at New York’s strategy for addressing changing long-term care needs and demand for direct care, there are two key factors that should be noted. New York State’s ability to use its licensing and medical authorization powers shows that the state’s move to swiftly create jobs can be a vital tool in expanding the role and power of direct care roles. Additionally, these roles can be piloted and reimagined to fit the changing care needs for those requiring long-term care. By working with unions, employers, patient advocacy groups, and regulators, New York State has shown its ability to lead in creating space for experimentation and growth within the industry.

**POLICY RECOMMENDATIONS**

Based on lessons drawn from these case studies, the current literature, and ideas discussed with community leaders, the following policy solutions are recommended for the state of Illinois. These policy recommendations are a framework for envisioning the future of the direct care industry in Illinois.
Regulatory Changes

Standardize Curriculum and Training Programs Across the State

Illinois lawmakers should seek to standardize the basic training requirements and competencies amongst all online, class-based, and clinical-based instructional providers. While different course curricula amongst different institutions are already relatively similar, standardized curriculum and instruction should level the cost of courses for employers and students seeking instruction. New institutions looking to offer instructional courses will not be burdened by individual curriculum development when one will already be offered by the state.

Develop Ranked Tier System of Training

Illinois should develop tiered systems of certification for direct care workers continuing their skills training. Like New York State’s Advanced Home Health Aide designation, Illinois can authorize differing levels of care and specialty. Specialties should include (but not be limited to) the expansion of the state’s mandated Alzheimer’s disease and dementia training, language certifications, HIV and AIDS care, trauma-informed care, and consumer education. By clearly defining care roles and requisite training involved, the state can ensure that agencies clearly adhere to specific services advertised and offered to clients. Workers will be protected against work contracts that are unfair and lack transparency, where they are compelled to carry out tasks outside their medical skillset or physical capabilities. Customers will also benefit from the assurance that staff will be properly trained and informed about the care environments workers will be stepping into.

The Ranked Tier System Should Translate into Recognized Academic and Community Credentials

Illinois should create academic partnerships with direct care training institutions. By formally creating pathways for learned core competencies to be translated into higher-level nursing courses or other college credit, direct care workers can finally be folded into the nursing education infrastructure of Illinois. Similar to SEIU 775’s training pathway system, Illinois should expand on the gained work experience of direct care workers by subsidizing apprenticeship programs, management training, and career pathways into research and allied health
careers. Direct care work should thus more robustly serve as a viable entry point into different ranges of professionalized direct care roles and other healthcare careers.

**Administrative Infrastructure**

Illinois should also lead the way in the creation of a Taft-Hartley multiemployer training and education fund with other stakeholder agencies and unions representing direct care workers. The state of Illinois is one of the largest employers of direct care workers, and thus has a major stake in developing a workforce for the public and private sector. This fund should be governed as a nonprofit school by a board of trustees representing unions, management, patient/consumer advocate groups, and researchers. The board would function as a professional regulatory body with the mission of broadening the importance of direct care work through research, evidence-based training, and access to direct care jobs. Through the administration of the fund and guidance to its education providers, the fund would function as a major clearinghouse for direct care training.

Contract bargaining amongst organized labor and employers will determine a large portion of funding, as well as the reliance on grants and revenue generation streams. The fund should seek to incorporate non-unionized employees such as independent providers, part-time workers, and non-unionized agencies through tuition-assistance programs and grants.

**Potential for State-Led Reform**

Political will and administrative burden are crucial when considering the potential for state-led reform of Illinois’s training and certification system. While Illinois can learn from examples like SEIU 775 and New York’s legislative approaches, it must also grapple with its own unique healthcare industry.

With the recent passage of a $15 minimum wage and Domestic Worker Bill of Rights that gives overtime and wage protections to direct care workers, Illinois lawmakers have shown the desire to support worker advancement. In a similar way to New York Governor Andrew Cuomo prioritizing a task force to explore the potential for AHHA roles before introducing the bill into the legislature, there will have to be coordination between the Illinois Department of Public Health,
Department on Aging, and Bureau of Labor to produce insight into specific integrated regulatory changes and start-up costs. A pilot program for the creation of new care roles and training initiatives can inform lawmakers on the potential impacts on workers, agencies, and consumers before moving on more sweeping reform.

Lastly, for large-scale training programs to succeed in later stages of implementation, there is also a need for widespread consensus and buy-in from unions and employers. Illinois must be able to create incentives for unions and employers to support a new training partnership and push for higher state training standards. Such incentives can include financial assistance in tax credits or grants, detailed sectoral research brought by larger scale surveying and data collection, and access to a more skilled workforce of certified individuals.

CONCLUSION

This policy proposal seeks to create clear state training standards and more accessible career pathways for direct care workers, providing them with knowledge, resources, and room for growth in their field of work. To better be able to recruit and retain direct care workers, Illinois must reform inadequate training structures while leading the way in expanding new care roles and career advancement pathways.

In the coming decades, the importance of direct care roles will continue to grow and change as employers, workers, and consumers continue to utilize these services. By performing close-up medical and non-medical services within a consumer’s home or care environment, direct care workers are able to oversee the continuum of care that occurs from hospital to home. As described by the Aspen Institute:

In this vision, [home care aides] are the front line in identifying potentially harmful symptoms or illnesses earlier, improving the speed and quality of care, and improving the quality of life for consumers and their families. Earlier identification, diagnosis and interventions can reduce emergency room visits and hospitalization, which reduces health care costs — for the consumers and the publicly funded health care systems (Choitz, Helmer, Conway 2015).

Over the next few years, changing best practices, increased use of telemedicine, and the devolution of certain nursing tasks in direct care will signify the dynamic nature of the field. Today, direct care workers are already seeing these changes,
but are not given a say in their ability to educate and prepare themselves for their clients. For example, the recent emphasis on mental health resources for those in long-term care is a reflection of unrecognized emotional support and companionship roles that direct care workers held for years. By formalizing training on topics such as trauma-informed care, culturally competent practices, and mental health first aid, direct care workers will undoubtedly be in a better position to care for those requiring long-term care.

When considering this framework for state-level change, it is important to understand that everyone has required and will require care from another individual at least once in their life, regardless of age or condition. Similar to the way in which Medicare and other long-term care programs must be supported to provide for our loved ones, direct care services must also be continually renewed and invested in as a public good. Workers in these fields understand the role they play in maintaining a humane and comfortable quality of life for the elderly and those requiring care. Illinoisans only stand to gain from supporting direct care workers in their economic and career development needs.
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Kevin Cao was a 2019–2020 Emerging Fellow and is now an active alum in the Roosevelt Network. He is a founder of the University of Illinois at Chicago Roosevelt chapter, which won the Best Chapter award in 2019. His policy areas of interest include health-care policy, aging and disability policy, and organized labor in health care. He is currently pursuing an MD at UICOM and looks forward to stepping back into the policy sphere.

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The Roosevelt Network trains, develops, and supports emerging progressive policymakers, researchers, and advocates, focusing on communities historically denied political power. With locations on campuses and in cities in nearly 40 US states, the network is founded on the principle that changing who writes the rules can help fulfill the promise of American democracy and build true public power. The network supports student-led, scalable policy campaigns that fight for the equitable provision, distribution, and accessibility of public goods at the campus, local, and state levels. In addition to its student-led activities, the organization leverages the power of its alumni network—which includes public officials, lawyers, teachers, nonprofit executives, and researchers—to expand opportunities for the next generation of policy leaders. A program of the Roosevelt Institute, the network operates alongside leading economists and political scientists to bring the ideals of Franklin and Eleanor Roosevelt into the 21st century.