



CARING
ACROSS
GENERATIONS

2018

Care Report

Card: Illinois



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Overview

As 10,000 people across the nation turn 65 each day, older adults are enjoying longer lives and spending more time with their loved ones. Although aging well is a source of joy, this unprecedented demographic shift is also putting an increased burden on our families, our finances, and our care system.

We should all be able to access the care we want and need at every stage of life. We should be free to live and age in the setting of our choice, and to be able to afford the care that makes this possible – all while supporting family caregivers and fairly compensating direct care workers, who themselves are aging and caring for loved ones.

Major investments in our transportation infrastructure changed how we live and work in the 20th century. Investing in a strong and sustainable care infrastructure can reduce growing inequities and improve quality of life in the 21st. We have an incredible opportunity to mobilize the Caring Majority – 100 million Americans who are family caregivers, professional caregivers, older adults, people with disabilities, and individuals in their networks – to create a care infrastructure that works for everyone.

Such an infrastructure must be sustainable, streamlined, and flexible enough to cover the full range of care options that almost all of us will need over the course of our lives: child care, long-term care, and paid family and medical leave. It should reflect how the majority of people actually want to live and age today by including strong benefits for home and community-based support and paid leave, inclusive of caregivers and older adults. It must value the essential work that family caregivers and care workers do, while promoting recruitment and retention for one of the country's fastest growing workforces. Finally, any benefit should be available and accessible to anyone who needs it, regardless of income or current job status.

Our vision of this infrastructure is the “Universal Family Care” (UFC) model. To provide a baseline assessment of our current care infrastructure, Caring Across Generations developed the **2018 Care Report Card**¹ as a resource for advocates, community organizations, and legislators in select states² working to advance and realize the vision of Universal Family Care. The indicators are organized by three key constituencies of the Caring Majority: aging adults and people with disabilities, family caregivers, and direct care workers. Each indicator identifies significant benchmarks toward achieving UFC and a care infrastructure that would work for all families.

¹ The information contained in this document reflects the information that we know to the best of our knowledge.

² Caring Across Generations is working with local advocacy groups or coalitions in select states to advance access to long-term services and supports. For 2018, we've created report cards for Illinois, Iowa, Maine, Michigan, Minnesota, New York, and Rhode Island.



Caring Majority Constituencies: Illinois

Care Recipients: Aging Adults and People With Disabilities

The senior population of Illinois will more than double by 2025 to 2.5 million,³ increasing the need for long-term services and supports (LTSS). There are 1.6 million Illinoisans between the ages of 55 and 64, and 2.3 million, or 15 percent of the population, are age 65 and older.⁴ Seventy percent of adults turning 65 today will need some form of long-term care in their lifetimes,⁵ 20 percent will need more than five years of care,⁶ and 90 percent of people want to live and age in their homes and community.⁷

Caring Across Generations supports initiatives that seek to:

- Increase access to care and care choices and
- Increase affordability of care.

Family Caregivers

Illinois's rapidly aging population means more families are having to support an aging family member, often while caring for children and working outside of the home. There are over 1.5 million family caregivers in Illinois caring for a parent, spouse, or loved one, providing over 1.4 billion hours of unpaid care annually at a value of \$1.8 billion.⁸ Family caregivers spend an average of almost \$7000 annually out-of-pocket for care for a loved one.⁹

Caring Across Generations supports initiatives that seek to improve the lives of family caregivers and to recognize the value of their work by:

- Tracking and training family caregivers;

³ "Home Care Workers in Illinois: Key Facts." PHI, November 2011. Accessed March 13, 2018. https://phinational.org/wp-content/uploads/2017/11/dcwillinois_factsheet16-web_0.pdf.

⁴ "Population Distribution by Age." Kaiser Family Foundation, 2017. Accessed March 13, 2018.

<https://www.kff.org/other/state-indicator/distribution-by-age/?dataView=1¤tTimeframe=0&selectedDistributions=65&sortModel=%7B%22colld%22:%22Location%22,%22sort%22:%22asc%22%7D>.

⁵ "How Much Care Will You Need?" Longtermcare.gov, October 10, 2017. Accessed March 13, 2018.

<https://longtermcare.acl.gov/the-basics/how-much-care-will-you-need.html>.

⁶ Pfau, Wade. "Costs and Incidence of Long-Term Care." Forbes, January 5, 2016. Accessed March 13, 2018.

<https://www.forbes.com/sites/wadepfau/2016/01/05/costs-and-incidence-of-long-term-care/#174422594ceb>.

⁷ "Aging in Place: A State Survey of Livability Policies and Practices." National Conference of State Legislatures and AARP Public Policy Institute.

December 2011. Accessed March 02, 2018. <https://assets.aarp.org/rgcenter/ppi/liv-com/ib190.pdf>.

⁸ "Valuing the Invaluable: 2015 Update." AARP Public Policy Institute, July 2015. Accessed March 02, 2018.

<https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>

⁹ Rainville, Chuck, Laura Skufca and Laura Mehegan. "Family Caregiving and Out-of-Pocket Costs: 2016 Report, November 2016. Accessed March 13, 2018. https://www.aarp.org/content/dam/aarp/research/surveys_statistics/lc/2016/family-caregiving-costs.doi.10.26419%252Fres.00138.001.pdf.



- Increasing supportive services and programs, such as case management and respite;
- Creating flexible workplace policies, like paid leave;
- Recognizing and valuing the work of family caregivers through policies such as wage replacement and tax credits; and
- Providing affordable, accessible childcare for members of the sandwich generation, who are providing care for an aging adult and a child at the same time.

Direct Care Workers

The direct care workforce is one of the fastest growing workforces in the country, yet Illinois faces a shortage of home care workers, especially in rural areas. In Illinois, this workforce expanded by nearly 40% between 2006 and 2016.¹⁰ Because wages and workplace benefits have stagnated, there is an anticipated shortfall in the workers needed to meet the demand. The state currently has no plans to address this looming crisis, even though, between 2014 and 2024, Illinois will need 17,900 new home care workers.¹¹ Care workers must be valued for the vital work they do, and their jobs should be high-quality jobs to reflect that.

Caring Across Generations supports:

- Increasing access to benefits and ensuring living wages for the care workforce,
- Increasing access to affordable training for workers and improving career mobility,
- Developing state recruitment and retention initiatives,
- Increasing worker representation and right to organize, and
- Ensuring a safe environment for all workers regardless of their immigration status.

¹⁰ "Home Care Workers in Illinois: Key Facts." PHI, November 2011. Accessed March 13, 2018. https://phinational.org/wp-content/uploads/2017/11/dckillinois_factsheet16-web_0.pdf.

¹¹ Ibid.



A Note about Childcare and Paid Family and Medical Leave

Some family caregivers, direct care workers, and even aging adults caring for a grandchild are sandwiched between providing childcare and supplementing the care of an aging or ill adult child, spouse, or loved one. In fact, over 211,000 households in Illinois have multiple generations (three or more)¹² living under one roof, meaning many families are likely caring for a child and an aging parent or loved one at the same time. In Illinois, the cost of childcare already exceeds the cost of in-state public college tuition.¹³ This compounding of child and elder care expenses puts paid care out of reach for most families, and makes working families financially vulnerable. Family caregivers and the direct care workforce need access to affordable childcare and flexible workforce policies, like paid leave, in order to balance the demands of care. Paid leave would allow caregivers to take time off to care for themselves and their loved ones without losing their jobs or their much-needed income.

¹² "Current Population Demographics and Statistics for Illinois by age, gender, and race." Suburban Stats, 2017. Accessed March 9, 2018. <https://suburbanstats.org/population/how-many-people-live-in-illinois>.

¹³ "Parents and the High Cost of Childcare: 2017." Child Care Aware of America, 2017. Accessed March 9, 2018. <https://usa.childcareaware.org/advocacy-public-policy/resources/research/costofcare/>.



Report Card

At Caring Across, we believe that the care system should work for everyone, especially care recipients, family caregivers, and the direct care workforce. Here is how Illinois measures up in meeting the needs of the members of the Caring Majority.

Overall grade:





1 of 3: Care Recipient		F
INDICATOR	NOTES	SCORE
Medicaid Expansion	In November 2013, Illinois expanded Medicaid, increasing access to more than 11.1 million people. ¹⁴	
Affordable LTSS	In 2015, the average median income in Illinois was \$59,588. ¹⁵ According to Genworth, the costs of care in Illinois range from \$51,480 for a home health aide to \$78,293 for a private room in a nursing home, putting LTSS out of the reach of many Illinoisans. ¹⁶	
Accessible LTSS	Due to gross underfunding of critical programs and service, a state budget crisis, and other barriers, including lack of workers in needed areas of the state, programs in Illinois have waiting lists.	
Sustainable Funding	Due to a dire budget crisis, programs throughout Illinois are critically underfunded, creating waiting lists and the inability to provide needed services.	
Expanded Affordability	Aging adults 60+ can access home and community based LTSS through the Illinois Department on Aging's Community Care Program (CCP). Services for eligible adults include adult daycare, homecare, and Emergency Home Response Services (EHRS).	
Community First Choice	Illinois does not offer the Community First Choice program.	
Avoiding Unnecessary Institutionalization	A nursing home deflection program, administered through the Illinois Department on Aging, aims to reduce the number of initial nursing facility placements at the time of hospital discharge, and to reduce the average length of stay in nursing facilities for short-term placements. The program serves individuals eligible for Medicaid, Medicare, and other publicly funded long term services and support (LTSS) programs as well as those who are ineligible for publicly funded LTSS programs.	
Consumer-Directed Care	Illinois offers Consumer-Directed Services which offer the freedom to hire, fire, and train workers, and determine how and when services are delivered.	
Streamlined Access to Info and Services	Illinois received a grant from the Administration for Community Living to develop and implement a single-entry point "No Wrong Door" statewide system. Outcomes of the grant are expected in 2019.	
Asset Protection	Illinois does not, through state statute, has no state statute to protect the incomes and assets of an individual needing or receiving care through public programs like Medicaid.	

¹⁴ "A Review of Medicaid Expansion in Illinois under the Affordable Care Act." The Institute for Illinois' Fiscal Sustainability, January 12, 2017. Accessed March 12, 2018. <https://www.civicfed.org/iifs/blog/review-medicaid-expansion-illinois-under-affordable-care-act>.

¹⁵ "Illinois Household Income." Department of Numbers. Accessed March 9, 2018. <http://www.deptofnumbers.com/income/illinois/>.

¹⁶ "Compare Long Term Care Costs Across the United States." Genworth, September 26, 2017. Accessed March 9, 2018. <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>.



2 of 3: Family Caregiver		F
INDICATOR	NOTES	SCORE
Broadest Definition of Family	There is currently no law in Illinois that encompasses Caring Across's comprehensive definition of family (see appendix).	
Care Team Inclusion	In 2015, Illinois enacted the CARE Act, which allows a care recipient to name a family caregiver in their medical records upon entering the hospital. The act also requires hospitals to provide detailed care instructions to the designated caregiver about the care needs of their loved one, including the administration of medications and other in-home needs.	
Maximum Financial Protections	Illinois does not protect spouses from impoverishment by allowing the maximum amount of asset protection for spouses through Medicaid.	
Caregiver Assessment	New regulations require Medicaid funded home and community-based programs to assess family caregivers. ¹⁷ However, this assessment tool is not uniform and is not yet being executed in all states. Furthermore, the assessment tool is not being required across all other state-funded programs.	
Caregiving Training	While the Illinois Respite Coalition and the Caregiver Support Program offers some training for family caregivers, the program does not have adequate reach due to lack of funding.	
Financial Value	Illinois does not have a state dependent care tax credit for family caregivers to recoup costs of caregiving. Additionally, there are no programs, outside of Medicaid, where family caregivers can get paid for providing care.	
Affordable Childcare	Illinois has the third highest costs of childcare in the country. In 2015, the median income in Illinois was \$59,588. ¹⁸ The average annual cost of center-based childcare is \$23,426, ¹⁹ which is well above 10% of household income.	
Paid Family and Medical Leave	Outside of Federal Medical Leave Act (FMLA), there is currently no law in Illinois that requires employers to offer paid or unpaid sick leave to employees.	
Services and Supports	Community supports and services for family caregivers in Illinois are provided through various local contracts with agencies and organizations, including the statewide Caregiver Support Program. ²⁰	
Affordable Respite	The Department of Human Services and the Illinois Respite Coalition work to provide free or low-cost respite services for family caregivers. Additionally, some public programs offer respite services.	

¹⁷ Kelly, Kathleen, Nicole Wolfe, et al. "Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home- and Community-Based Service Waiver Programs." AARP, December 2013. Accessed March 9, 2018. <https://www.aarp.org/home-family/caregiving/info-11-2013/including-family-caregiver-assessment-in-medicaid-hcbs-waive-programs-AARP-ppi-ltc.html>.

¹⁸ "Illinois Household Income." Department of Numbers. Accessed March 9, 2018. <http://www.deptofnumbers.com/income/illinois/>.

¹⁹ "Parents and the High Cost of Childcare: 2017." Child Care Aware of America, 2017. Accessed March 9, 2018. <https://usa.childcareaware.org/advocacy-public-policy/resources/research/costofcare/>.

²⁰ While these services exist, they are grossly underfunded, eligibility is prohibitive and the data to track utilization of these programs remains inadequate.



3 of 3: Direct Care Workforce		F
INDICATOR	NOTES	SCORE
Worker Shortage	By 2022, Illinois will need more than 35,000 more direct care workers. ²¹ Yet, Illinois does not have a statewide plan to recruit and retain workers.	
Wage and Overtime Protections	In 2016, Illinois passed a law giving workers, such as homecare and domestic workers, wage and overtime protections.	
Wage Pass-Through	Illinois requires a minimum of 77% of total revenues from the state to be spent on direct service worker costs. Those costs include: wages, paid leave, health coverage, retirement coverage, and travel time and reimbursement. Those providers not in compliance are required to submit corrective action plans and are subject to termination.	
Career Advancement and Training	Illinois does not offer advanced roles for care workers. Additionally, there are no standardized training requirements across the different types of homecare positions. There also is no industry-wide recognized statewide training program to lead to positions across the medical service industry.	
Medicaid Expansion	In November 2013, Illinois expanded Medicaid, increasing access to more than 11.1 million people, including direct care workers.	
Affordable Health Coverage	With the average salary for homecare workers in Illinois around \$24,000 per year, ²² many home care workers must rely on Medicaid for health insurance. The cost of private-market coverage puts non-Medicaid care out of reach for most low-wage workers.	
Affordable Childcare	At \$23,426, Illinois has the third highest costs of childcare in the country. The cost of childcare exceeds 10% of average household income.	
Paid Family and Medical Leave	Outside of FMLA, there is currently no law in Illinois that requires employers to offer paid family and medical leave to employees.	
Treatment of Immigrant Workers	Illinois is a sanctuary state, offering interventions to protect all immigrant workers.	
Worker Organizing	Illinois has maintained strong unions and worker representation and does not currently have any "right-to-work" laws.	

²¹ "Home Care Workers in Illinois: Key Facts." PHI, November 2011. Accessed March 13, 2018. https://phinational.org/wp-content/uploads/2017/11/dckillinois_factsheet16-web_0.pdf.

²² "May 2016 State Occupational Employment and Wage Estimates Illinois." U.S. Department of Labor, Bureau of Labor Statistics, May 2016. Accessed March 9, 2018. https://www.bls.gov/oes/current/oes_il.htm.



Conclusion

Although legislative progress has been made in Illinois, families are still struggling to make ends meet while addressing their caregiving needs. On top of that, the baby boomer generation is growing at a record pace and people are living longer than ever before. Rising costs, the lack of support for family and professional caregivers, and Illinois's rapidly expanding aging population all require immediate and comprehensive solutions. We need to build a sustainable 21st-century care infrastructure that works for today's families and turns care jobs into good jobs. There has never been greater urgency or opportunity to reimagine how we care for one another.

Appendix: Indicators

For each population of the Caring Majority, Caring Across identified the top indicators based on key components needed to expand access, protect the Caring Majority, and progress toward achieving universal long-term care. Points were awarded a thumbs up for affirmative answers posed below for each indicator. The indicators are:

Care Recipients

1. Medicaid Expansion: *Has the state expanded Medicaid?*

With the passage of the Affordable Care Act in 2010, states were allowed to expand their Medicaid programs to families with incomes up to \$26,347 and individuals with incomes up to \$15,417. States who expanded their programs received a financial match from the federal government to make expansion financially feasible. This means that people who made too much to qualify for Medicaid but not enough to afford private insurance could now gain access to affordable care through expanded Medicaid - and specifically home- and community-based services if their state expanded Medicaid.

2. Affordable LTSS: *Is long-term care affordable?*

Long-term services and supports (LTSS) are defined as the services and assistance provided to individuals of all ages needed to perform a range of daily activities, such as bathing, dressing, preparing meals, and administering medications. Rising costs year after year have put these needed services out of reach for many individuals and families. To be affordable, the cost of care should not exceed 10 percent of the average household income in that state.



- 3. Accessible LTSS:** *Is the state effectively matching individuals and families who need care with the care services they need within the identified time of care needs? (i.e. Is the state free of waiting lists for LTSS programs and services?)*

In some places, older adults, people with disabilities, and their caregivers may be eligible for homecare services, but due to inadequate funding, market volatility due to program threats at the federal level, or a shortage of care workers, individuals can wait for months for critical services. Individuals and their families should be able to access the care they need, when they need it.

- 4. Sustainable Funding:** *Are public and private programs for care and caregiving adequately funded to meet current needs, with built-in increases that account for inflation and growing costs of care?*

Adequate funding for critical programs allows all individuals and their families to access the care they need, when they need it. Many programs were established with the intent of meeting this goal but have been underfunded due to competing state revenue priorities and a lack of progressive revenue development. This means that individuals who need critical services are unable to access the care they need. Funding streams for critical safety net programs and programs that support aging adults, people with disabilities, and their caregivers should have a dedicated and protected stream of funding that increases with inflation and demands based on the needs of people.

- 5. Expanded Affordability:** *Is there a statewide program that helps individuals who do not qualify for Medicaid access and afford services?*

Many people with incomes just above the Medicaid eligibility criteria still struggle greatly to afford care. Some states have begun to recognize this need by offering additional financial support for LTSS services to more families above the Medicaid threshold.

- 6. Community First Choice:** *Does the state offer Community First Choice?*

Community First Choice (CFC) is a program that incentivizes states to provide care in a home setting over the default of providing care in an institutional setting. CFC offers higher reimbursement rates for consumer-directed home and community-based services for individuals who would otherwise receive care in an institution.

- 7. Avoiding Unnecessary Institutionalization:** *Does the state assess individuals for community services over institutional services to divert or transition individuals from unnecessary nursing home and institutional placement?*

Ninety percent of people prefer to age with dignity in their home as long as possible. Public programs, which set the standard for care delivery, have been biased toward institutionalized services. This biased practice has led to individuals being wrongly institutionalized or staying in nursing homes



longer than necessary without a transition plan to get them home when appropriate.

- 8. Consumer-Directed Care:** *Does the state have consumer-directed programs, offering **consumers** or family caregivers major control and decision-making power regarding their care and services, including controlling how and when services are provided and by whom?*

People want to be able to choose how they receive their services and who they can hire as their caregiver. Founded in the independent living and disability rights movement, the ability to maintain power over one's decisions is critical in getting the type of dignified care individuals and their families want and need. Consumer-direction honors an individual's right to retain control of their lives, their decisions, and their ability to participate fully in decisions about healthcare.

- 9. Streamlined Access to Information and Services:** *Can people go to a single, streamlined point of entry for eligibility and access to all senior and long-term care service programs in the state?*

When families need long-term care, they are often left scrambling to find the services available to them. Having an accessible reliable source of information can make it easier for people to navigate the myriad complex systems, programs, and services they may encounter in trying to meet their long-term care needs.

- 10. Asset Protection:** *Does the state offer any protections above the federal Medicaid threshold for the incomes, assets, and savings of individuals needing care?*

Many people spend down to poverty levels just to access the care they need through public programs, which is a silent driver of economic inequality in America. States vary widely in the protections they offer, from nothing at all to protecting property, savings, retirement savings, and spousal income from being counted as assets and income.

Family Caregivers

- 1. Broadest Definition of Family:** *Has the state adopted the broadest and most inclusive and expansive definition possible for "family" to include blood and chosen family?*

Many states still define family within a very narrow scope, usually limited to spouses and birth children. However, millions of families today include same-sex partners, adopted children, extended family through community - and many networks of caregiving often extend beyond what states define as family. CAG defines family member as an individual with any of the following relationships to the eligible employee:



- (a) spouse and parent of the spouse;
- (b) a child and spouse of the child;
- (c) a parent and spouse of the parent;
- (d) any sibling and spouse of the sibling;
- (e) a grandparent and spouse of the grandparent;
- (f) a grandchild and spouse of the grandchild;
- (g) a domestic partner and parent of the domestic partner, including the domestic partner of any individual
- (h) any other individuals related to the eligible employee by blood or whose close association with the eligible employee is the equivalent of an acknowledged family relationship."
- (i) a child includes not only a biological relationship, but also a relationship resulting from an adoption, step-relationship, and/or foster care relationship, or a child to whom the Employee stands in loco parentis.
- (j) a parent includes a biological, foster, stepparent or adoptive parent or legal guardian of an Employee, or a person who stood in loco parentis when the Employee was a minor child.

2. Care Team Inclusion: *Are providers required to document and track family caregivers?*

Family caregivers are a critical component of an individual's care team. Without documenting and tracking family caregivers, providers can miss out on critical opportunities to get updated and accurate information about people's health conditions.

3. Maximum Financial Protections: *Are the incomes, savings, and assets of family caregivers, like spouses, protected to the maximum amount allowable by federal law?*

Some public programs, including Medicaid, count the income and assets of a spouse when determining financial eligibility. This threatens the income security of the spouse and family, often resulting in the need to liquidate shared assets. This practice impoverishes individuals and families. The federal government allows state Medicaid programs to protect the assets of spouses and immediate family caregivers up to \$120,900 for 2017. While states cannot establish a threshold above this amount, many states fall well beneath this asset protection level.

4. Caregiver Assessment: *Are caregivers assessed for their own needs?*

Caregivers have a unique set of needs and challenges. Assessing a family caregiver's emotional, mental, and physical needs, strengths, and weaknesses, as well as the ability of the caregiver to contribute to the needs of the care recipient, allows the state to be responsive to caregivers' needs. States need to recognize the importance of caregiver assessments and implement them for all programs that rely on a family caregiver as part of the care infrastructure. This also helps family caregivers feel acknowledged,



valued, and understood by service providers.

- 5. Caregiving Training and Resources:** *Are there adequately funded public training programs and/or robust educational resources for caregivers that are free or affordable?*

Family caregivers are often thrown into a set of responsibilities they are not trained to handle, such as skillfully bathing and transporting their loved ones and managing and administering medicines. Access to affordable training can lead to empowered caregivers and higher quality of care for those they care for.

- 6. Financial Value:** *Does the state offer a stipend, income replacement, or dependent care tax credit for all family caregivers to offset the out-of-pocket expenses shouldered by caregivers?*

According to AARP, family caregivers spend up to \$7,000 out-of-pocket on the care needs of a loved one. Additionally, family caregivers often make work adjustments that can compromise their earnings and future income and retirement security. States need to value the hard work and contributions of family caregivers and prevent their contributions of care from becoming a financial burden that threatens their own economic security.

- 7. Affordable Childcare:** *Is the average cost of childcare less than 10 percent of the average household income?*

Known as the sandwich generation, family caregivers can be sandwiched between providing care for an aging loved one while simultaneously providing care for a child. These costs, experienced at the same time, can be financially devastating for families.

- 8. Paid Family and Medical Leave:** *Is there paid family and medical leave that provides family caregivers, direct care workers, and working aging adults job protection and income replacement?*

Family caregivers are often balancing care for an aging loved one while working full-time. Flexible leave policies that allow workers to care for their loved ones without losing wages and compromising their job is critical to income security. As of January 2017, California, New Jersey, New York and Rhode Island, have passed and implemented paid family and medical leave. Both Washington, DC and Washington state have passed their paid family leave laws and benefits are scheduled to start in 2020.

- 9. Caregiver Services and Supports:** *Are there state services that specifically support family caregivers like case management and support groups?*

Family caregivers need help and support to feel equipped and empowered to provide care to their loved ones while maintaining a healthy work-life balance. Supports help family caregivers feel valued, avoid burnout, feel



connected in their experiences, and maintain physical and mental health.

10. Affordable Respite: *Do family caregivers have access to respite programs?*

The work of caregiving is honorable, rewarding, demanding and hard. Caregivers need respite - an occasional break to take care of themselves and manage the demands of their own lives outside and inside of caring for their loved ones. Rest is essential for reducing stress so that caregivers can give their best.

Direct Care Workers

1. Worker Shortage: *Does the state have a plan to recruit and retain direct care workers to keep up with the increasing demand for long-term care?*

As the population ages, more and more people will need care. As people are less and less able to rely on family members to care for them, a strong direct care workforce will be critical to meet this demand. As it stands, there is a shortage of care workers in many states, especially in rural areas. Additionally, the direct care workforce experiences high turnover rates. A lack of workers means individuals who need care may be left without it.

2. Wage and Overtime Protections: *Do direct care workers, particularly home care workers, receive minimum wage and overtime protections that is better than the federal standard?*

Home care workers provide an estimated 75 percent of paid, hands-on care; yet they are paid poverty wages, averaging \$10.49 per hour. Increasing wages, ensuring workers are paid for all time worked, and enforcing labor protections are essential to attracting and retaining the workers needed to meet unprecedented demand.²³

3. Wage Pass-Through: *Does the state require a set percentage of Medicaid payments to be applied directly to the wages of direct care workers?*

Many providers want an increase in the reimbursement rate for services provided through Medicaid. Wage pass-through requires a certain percentage of funds be spent on worker wages and benefits. Wage pass-throughs not only invest in the much-needed workforce, but allow providers to draw on federal and state dollars to supplement the cost of higher wages.

4. Career Advancement and Training: *Can direct care workers advance their careers through affordable training in the state, as well as opportunities to apply*

²³ "Home Care Worker Rights in the States After the federal companionship rules change 2016." National Employment Law Project, August 2016. Accessed March 9, 2018. http://www.nelp.org/content/uploads/State-chart-on-companionship-regs_revised_August-2016_Final.pdf.



their experience toward more advanced healthcare positions and across disciplines?

Training is critical for developing the skills of workers, professionalizing the workforce, and improving wages. Workers also need to be able to apply their skills and experiences toward more advanced healthcare positions.

5. Medicaid Expansion: *Can direct care workers access health insurance through expanded Medicaid?*

Due to low wages, many direct care workers rely on Medicaid to meet their own health care needs. With over 50 percent of the direct care workforce relying on Medicaid, expanding Medicaid means increased access to healthcare for more workers. To do their work effectively, workers need to be healthy and should be able to access affordable, quality care for themselves and their families.

6. Affordable Health Coverage: *Can most direct workers afford health insurance outside of Medicaid?*

Rising premiums put private health insurance out of the reach of many workers and their families. Statewide healthcare programs that assist workers in accessing and paying for care allow them to stay healthy and do their work well. Healthcare should not consume more than 10 percent of a worker's income.

7. Affordable Childcare: *Do direct care workers have access to affordable childcare?*

Childcare costs should not consume more than 10 percent of a worker's income. Direct care workers have to balance low-wages with the realities of daily costs of living, including childcare. Current childcare costs strain already low wages. While some workers qualify for childcare subsidies, childcare should be affordable for all.

8. Paid Family and Medical Leave: *Do direct care workers have statewide access to paid family and medical leave?*

Direct care workers, especially hourly workers, need increased access to workplace benefits in order to care for themselves and their own families, even as they assist and support aging adults and people with disabilities as their clients. Paid leave laws should require job protections and wage replacement for all workers, with special consideration for low-wage workers.

9. Treatment of Immigrant Workers: *Does the state protect undocumented workers?*

Immigrant workers comprise nearly one quarter of the current direct care



workforce.²⁴ Individuals receiving long-term services and supports rely on continuity of care without unnecessary disruption. All workers need to live and work in a safe environment without the threat of harassment. States should limit or prohibit engagement with mass deportation actions, local police should be prohibited from acting as ICE agents or as being a gateway to ICE, and all immigrants should be offered equitable protections, regardless of what industry they work in.

10. Worker Organizing: *Has the state successfully fought attacks, such as the passage of “right-to-work” laws, that attempt to weaken the ability of workers to organize?*

The ability for workers to organize and unionize leads to increased industry standards and higher quality benefits such as higher wages, training, and healthcare. Organized workers can negotiate wages, benefits, and establish appeals processes to fight against injustices with corporations of all sizes and with the state as an employer. Unions help establish industry practices for wages, training, and benefits.

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²⁴ Espinoza, Robert. “Immigrants and the Direct Care Workforce.” PHI National, June 2017. Accessed March 9, 2018. https://phinational.org/wp-content/uploads/2017/06/immigrants_and_the_direct_care_workforce_-_phi_-_june_2017.pdf.