



CAREGIVERS AT RISK:

*The urgent need for **fair pay and paid leave** for all of NC's caregivers*

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Key Findings:

- The vast majority of long-term care happens at home and in the community. Direct care workers such as home health aides and unpaid caregivers, usually family members, are the foundation of the long-term services and supports system. Unfortunately, caregiving – both paid and unpaid – has long been undervalued. The lack of supportive workplace policies and protections for caregivers undermines the economic security of those who provide care.
 - Four statewide trends create urgency in addressing workplace standards of both the direct care workforce and family caregivers: the state is rapidly aging; the availability of potential family caregivers is declining; low-wage jobs are on the rise; and state investments in crucial supports for North Carolina's older adults and their caregivers are shrinking.
 - The direct care workforce is one of the lowest paid occupations in the state, with a median wage of \$9.05 per hour for home health aides. The financial impact of family caregiving is also well documented. The majority of direct care workers and the majority of low-income workers in North Carolina – many of whom provide informal care – lack access to earned paid sick days.
 - In addition to adequately funding support services for elderly residents and their caregivers and assuring access to health care for all, policy makers have the opportunity to address the “care gap” in a responsible manner by creating good jobs. Increasing wages and benefits for direct-care workers – and all workers in low-wage industries – is a critical step in meeting the care gap. All caregivers need good jobs to provide quality care.
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Introduction

North Carolina, similar to the rest of the country, is undergoing a major demographic shift. Our state is currently home to about 1.3 million residents aged 65 and older.¹ By 2030, this population is expected to increase to a whopping 2.2 million.²

The rapid aging of our state will lead to a surge in community members who will need assistance. It is likely that just about every one of us will eventually be called upon to either directly help our loved ones with daily activities like eating, getting dressed, and going to the bathroom, or to help pay for a professional's assistance with these activities of daily living.

Most long-term care happens at home and depends on two types of caregivers. The first are family members or close friends (unpaid "family caregivers"), most of whom also have separate paid employment. The second are direct care workers such as home health aides, those employed by a home health agency or by a family to provide care. Many direct care workers also have family care responsibilities, so have a dual role as both paid and unpaid caregivers.

Working family caregivers and paid direct care workers are a distinct but overlapping demographic with some important similarities. Both groups are dominated by women and the numbers show that the prospect of financial hardship is a reality for almost all direct care workers and many working family caregivers.

In addition to the important policy proposals and solutions specific to the direct care occupations and to low-income workers with family care responsibilities, there is a need to address the basic workplace standards of all caregivers.³ Fair wage standards and paid leave are at the core of lifting up the importance of care work, providing economic security to this vital work force, and providing the best possible care to our loved ones.

Caregivers (paid and unpaid) provide the foundation for our loved ones to be able to continue living with dignity. Our state's demographic shift and the ensuing growing demand for long-term care options give policy makers the opportunity to advance policies that provide good jobs that translate to quality care.

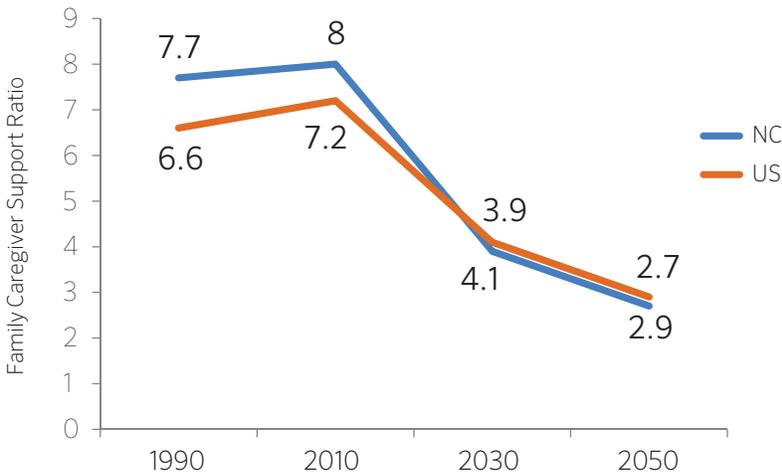
Four statewide trends create urgency

Four trends create particular urgency for addressing the workplace standards of both paid and unpaid caregivers in North Carolina: the state is rapidly aging; the availability of potential family caregivers is declining; low-wage jobs are on the rise; and state investment in programs that support older adults and their caregivers is on the chopping block.

■ The elderly population—and the population of those with functional limitations—is growing.

The growth in the elderly population will likely correspond with a significant increase in community members with functional and cognitive limitations.⁴ Among the population aged 85 and older, approximately two-thirds report functional limitations or physical problems that limit daily activities such as dressing, eating, and bathing.⁵ Our state already ranks 11th in the size of the population that is over 85 years old, and by 2030 this age group will be the fastest growing group of those above 65.⁶

FIGURE 1: The ratio of available family caregivers to those likely needing care is projected to drop dramatically over time.



SOURCE: Redfoot, Donald, Lynn Feinberg, and Ari Houser, 2013. “The Aging of the Baby Boom and the Growing Care Gap: A Look at the Future Declines in the Availability of Family Caregivers,” AARP Public Policy Institute.

■ **The number of potential family caregivers is shrinking**

In addition to the rapid aging of North Carolina’s population, the number of potential family caregivers (aged 45-64) available to care for those aged 80 and older is decreasing. Due in part to transformations in family size and compositions, the “family caregiver support ratio”—the ratio of the number of people of common caregiving age divided by the number of those most at risk of needing long-term care—is expected to decrease dramatically over time. In North Carolina the support ratio is expected to drop from 8 percent in 2010 to 2.7 percent in 2050 (see figure 1).⁷

These two demographic trends could reasonably be expected to place additional stress and strain on existing family and paid caregivers and to increase the need for paid services. The third trend, the rise of the low-wage labor market, is cause for concern for both direct care workers and working family caregivers.

Growing Old - by Margaret Toman, Garner, NC

My mother is 100 now, and has advanced Alzheimer’s Disease. Because she can no longer speak intelligibly I can’t always tell if she is in pain, if she is hungry, if she needs to go to the bathroom, or if she would prefer to sit here rather than there. For 14 years I have provided my mother the most attentive, proactive,

knowledgeable, loving care that I possibly can, advocating for her as only someone who knows her every nuance could do.

But we are the last of the family line. For me, and for thousands like me in our culture who are becoming “the only ones left” as the population ages, there remains the dilemma of who will

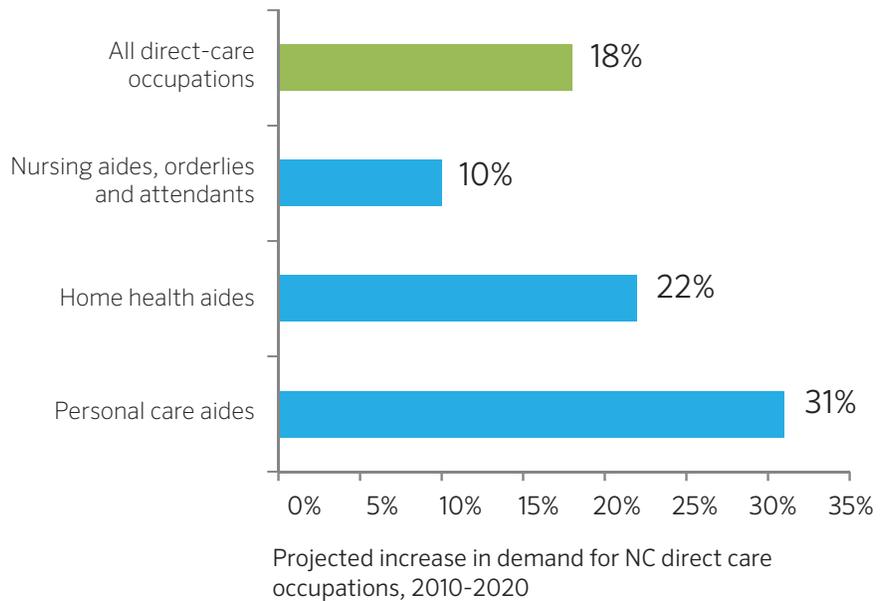
provide such care for us. Who will act as our health care proxy? How will we find one? Who will want to know us well enough to advocate for us accurately and effectively? Few want to assume this sensitive, intuitive role for a non-family member, leaving a gap we must figure out how to fill for sole survivors.

■ **Low-wage jobs are replacing jobs that provide a shot at the middle class.**

Over the past decade, North Carolina has experienced a decline in middle-wage jobs and an explosion in jobs that pay too little to lift families out of poverty. From 2000 to 2012, the number of poverty-wage jobs – or jobs that paid less than \$23,483 per year – grew by 19 percent while middle-class, middle-wage jobs (jobs paying between \$28,767 and \$43,950 per year) declined by 10 percent. In 2012, more than 3 in 10 workers in our state earned at or below the official poverty level.⁸

The home health occupation falls squarely within the category of poverty-level jobs and it is one of the occupations projected to experience the most growth nationwide and in North Carolina (see figure 2).⁹ North Carolina already has one of the highest home health occupational employment levels in the country with 47,860 home health aides – or 12.13 home health aides per 1,000 jobs – recorded in the country.¹⁰ Home health jobs are expected to increase by 22 percent in North Carolina by 2020 (see figure 2).

FIGURE 2: The demand for direct care workers in North Carolina is expected to increase over time.



SOURCE: PHI analysis of 2010-20 occupational employment projections accessed at <http://www.phinational.org/sites/phinational.org/files/state-by-state-demand-for-dcws-2010-2020.pdf>

■ **North Carolina’s investment in critical programs targeted at older adults and their caregivers is declining.**

Despite the fact that the demand for services to allow older North Carolinians to stay in their homes is on the rise, recent actions and proposals by state lawmakers cut precisely those programs aimed at supporting older adults and their caregivers. For instance, Project C.A.R.E. (Caregiver Alternatives to Running on Empty), a national best practice model designed and tested in North Carolina that provides respite services for family caregivers of relatives with dementia, lost significant state funds in 2011.¹¹ More recently, in the 2014 short session, Senate leadership pushed to cut nearly \$1 million from the Home and Community Care Block Grant (HCCBG), a state-federal program that funds services such as home-delivered meals, in-home aide, and transportation assistance. The HCCBG is the primary funding source for non-Medicaid funded home and community based services for elderly adults in our state.¹² The recently released House budget makes no cuts to the Block Grant and the final budget, as of this writing, has yet to be determined.

On the heels of the failure to expand Medicaid in 2013, a move that denies coverage to over 500,000 low-income state residents, recent Senate proposals also eliminate coverage for nearly 12,000 elderly, blind, or disabled people. And lawmakers have proposed eliminating Medicaid coverage for those who qualify as “medically needy” (except in those categories in which the State is limited by the maintenance of effort requirement of the Affordable Care Act).¹³ Notably, many North Carolinians qualify as “medically needy” because of high home care costs.¹⁴

These proposed cuts have a direct and indirect impact on our growing elderly population and those who care for them. Not only do these actions deny some of our most vulnerable state residents access to health care, they reduce funding and support for both paid services and family caregivers at a time when caregiving needs are on the rise.

These four trends create a need for increased state investment in programs that support our rapidly aging state, but also provide an opportunity to create a practical, meaningful plan for our aging state. Increasing wages and benefits for direct-care workers – and all workers in low-wage industries – is a critical step in meeting the care gap in a responsible manner.

Three steps toward creating quality jobs for all caregivers

STEP 1: Provide direct care workers with a living wage.

Many of those who work in caregiving occupations are motivated by a heartfelt desire to help. A look at the median wages and typical work supports of these occupations, however, makes it clear that workers stay in their jobs despite, not because of, wages or benefits.

Regina's Story

by Regina F., Greensboro, NC



I'm a CNA [Certified Nursing Assistant] and I have been in the health care field for 15 years. A typical day for me in home care is providing light housework like cooking, cleaning, taking out trash, doing laundry, medication reminding, taking vital signs – these are major necessities for my clients.

...We as CNA's have a very strong need for better pay. We provide 85 percent of services for in-home care, but we are underpaid for those services. We, as home care workers, have families as well and sometimes the pay just isn't adequate... It makes it hard for us to care for our own families. I'm hoping that we can be recognized more and that we will get the earnings needed to keep home care available to these clients who depend on us.

The direct care workforce is one of the lowest paid occupations in the state, with a median wage of \$9.05 per hour for home health aides (see figure 3). A full-time home health worker could expect to bring home approximately \$18,800 per year, which is almost exactly the federal poverty level for a family of three (one adult with two children).¹⁵ Of course, that assumes one is working full-time, year-round. The industry is known for its part-time nature, which means workers are falling short of even the meager federal poverty level.

In addition to already low wages, home health care has consistently appeared at the top of the list of industries in which wage theft – the underpayment or nonpayment of earned wages – occurs.¹⁶ Although enforcement data likely undercounts the true occurrences of wage theft, it is telling that over the last three years, the third highest number of complaints filed with

the NC Department of Labor's Wage and Hour Division has been in home health. Over 400 complaints were filed in 2013 (see figure 4).¹⁷

The low wages and high risk of wage theft combined with limited benefits in the direct care industry (30 percent of the care industry in North Carolina remains without any type of health insurance) can translate to job instability or simply the inability to make ends meet despite steadily working.¹⁸ Shockingly, almost half (45 percent) of direct care workers in North Carolina are on at least one type of public assistance.¹⁹ Raising the wages of direct care workers is a critical step toward ensuring basic fairness to these workers, as well as quality care to those in need of in-home assistance.

Overdue labor protections for direct care workers

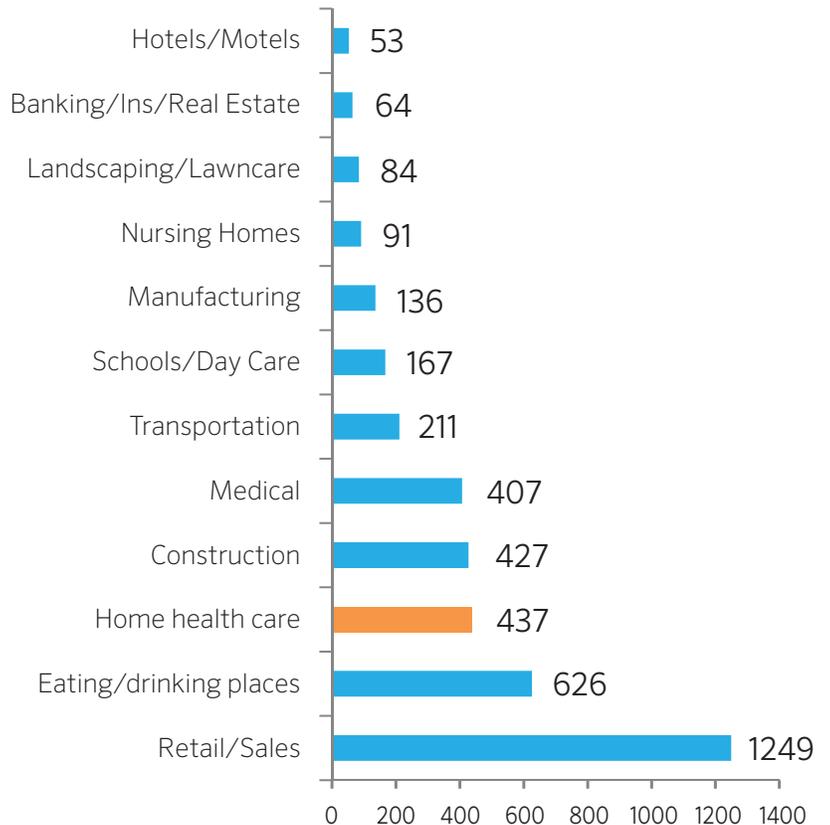
Low wages in direct care are steeped in the history of domestic work and exclusions from federal labor standards. Most workers have been guaranteed the right to a minimum wage and overtime pay for 75 years through the Fair Labor Standards Act (FLSA). But home care workers were considered "companions" and excluded from those protections until recently. Finally, on September 17, 2013, the U.S. Department of Labor published regulations to extend federal Fair Labor Standards Act protections - including the right to be paid the minimum wage and overtime - to most home care workers. The victory was hard fought and is long overdue. The regulations go into effect on January 1, 2015.

FIGURE 3: The median wages of North Carolina's direct care occupations are some of the lowest wages in the state.

	Median Hourly Wage	Median Annual Wage
Personal care aides	\$9.04	\$18,803
Home health aides	\$9.05	\$18,824
Nursing Assistants	\$10.74	\$22,339
All NC occupations	\$15.46	\$32,157

SOURCE: Bureau of Labor Statistics, May 2013 Occupational Employment and Wage Estimates, North Carolina (annual wage assumes a 40-hour work week, 52 weeks per year)

FIGURE 4: Over 400 wage violation complaints were filed within the home health industry in 2013.



SOURCE: Special data request to NC Department of Labor's Wage and Hour Division, 2014

STEP 2: Recognize that low-income workers may also be family caregivers.

Most (72 percent) older adults who need paid care also rely on a family caregiver and most (74 percent) persons with eldercare responsibilities also work at a paying job while caregiving.²⁰ Quality care depends on informal and formal caregivers being able to do both their caregiving and other jobs and to do them well. And this requires adequate workplace standards for all workers.

North Carolina's family caregiving workforce is considerable. Our state is home to approximately 1.18 million family caregivers who donate 1.1 billion hours of care, with an estimated economic value of \$11.7 billion.²¹ The Congressional Budget Office recently estimated that the value of that donated care nationwide totaled approximately \$234 billion in 2011, which may be a vast understatement since many caregivers sacrifice paid time to provide unpaid care.²² The "average" caregiver in the U.S. is a 49-year-old woman who spends nearly 20 hours of unpaid care per week while also working outside the home.²³

Although family caregiving is not tracked as an official occupation, the financial effects of caregiving on this largely invisible, often isolated unpaid workforce has been well documented through recent surveys. A 2009 survey found that more than one in four adult caregivers reported feeling a moderate to high degree of financial hardship as a direct result of caregiving.²⁴ Another study on the Great Recession's impact on family caregivers' financial situations found that half of the caregivers surveyed said that the economic downturn increased their stress about being able to continue caring for their loved ones.²⁵

Family caregivers don't just lose income because they lose paid work time in order to provide care to their loved ones. They also often pay out-of-pocket expenses to help support paid care for a family member with disabilities or chronic conditions. One survey found that those caring for family members or friends over the age of 50 spent more than 10 percent of their annual wages on caregiving expenses. The lowest-income caregivers (those earning less than \$25,000 per year) spent more than 20 percent of the annual income on these expenses.²⁶

The Gender Gap in Caregiving

- Almost two-thirds (**65 percent**) of family caregivers are women.²⁷
- More than nine in ten (**92 percent**) of direct care workers in North Carolina are women.²⁸



STEP 3: Provide all caregivers the opportunity to take time to care.

A recent AARP study found that one in five workers expected they would need to take family leave in the next five years. For Hispanic and African American workers this proportion was even higher – one in four African American workers reported expecting to take workplace leave because of caregiving responsibilities.²⁹

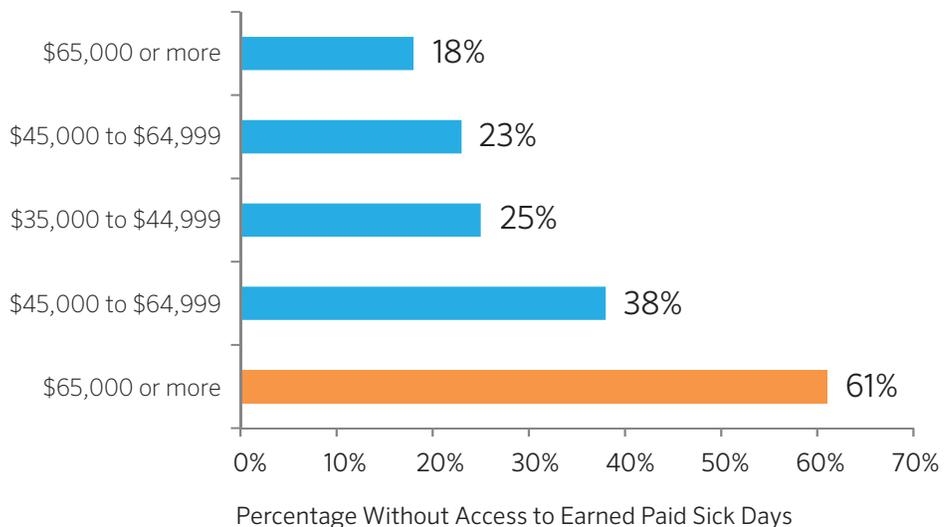
According to the AARP, “the best protection for working caregivers is having ample access to paid leave to care for an older relative or family member with a disability.”³⁰ Yet the data show that the majority of low-wage workers simply don’t have access to short or long-term paid leave.

In North Carolina, more than six out of ten (61 percent) full-time workers earning less than \$20,000 per year have no access to earned paid sick days. This is a stark contrast to those in the income level above \$65,000 in which only 18 percent lack access to paid leave that could be used for caregiving responsibilities (see figure 5).³¹

The lack of access to earned paid sick days in the direct care industry is particularly heartbreaking. Direct care workers have one of the most physically demanding jobs in the health sector and have close daily contact with vulnerable populations, yet the vast majority have no earned paid sick days to recover from injuries or illness. In North Carolina, almost seven out of ten (69 percent) full-time direct care workers lack access to earned paid sick days (see figure 6).³² This means that thousands of care workers in North Carolina will eventually face an impossible choice: call in sick and lose wages or possibly even a job, or work sick and risk their health as well as that of the person they assist.

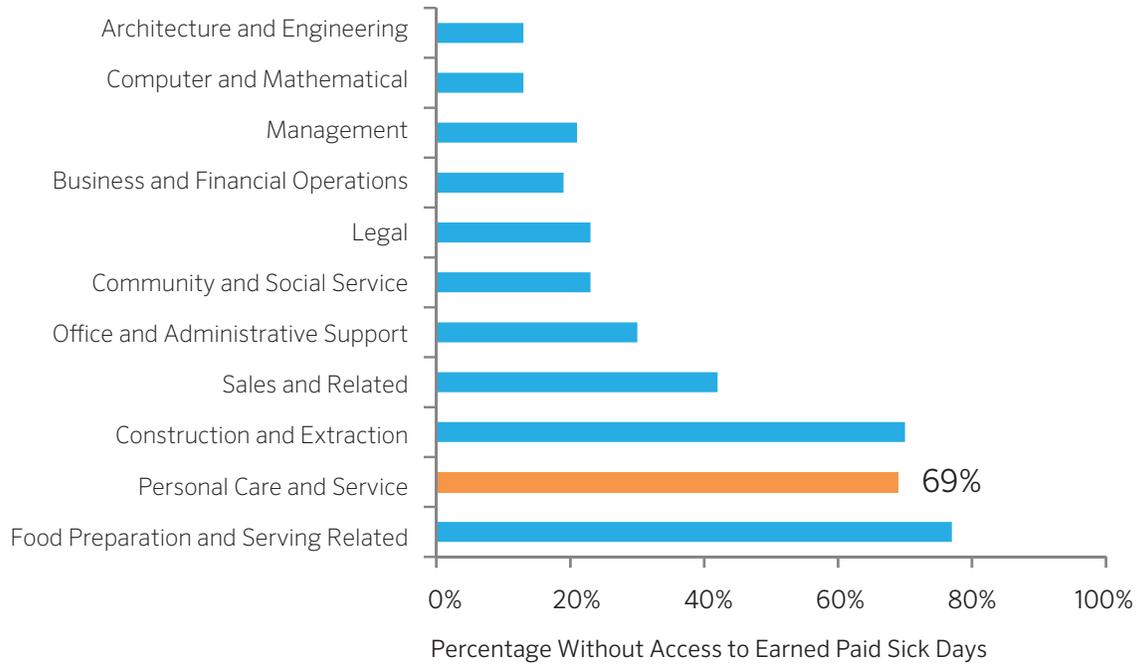
Despite the fact that low-income workers, including direct care workers, also tend to have more demanding family caregiver responsibilities than better paid workers, they are also the group

FIGURE 5: The majority of North Carolina’s low-income full-time workers have no access to earned paid sick days.



NOTE: Access rates are for individuals, 18 years and older, working in the private sector in North Carolina area regardless of their place of residence. For the analysis of access rates by personal income levels, the sample was also limited to only full-time year-round workers. Percentages and figures may not add to totals due to rounding. Source: Institute for Women’s Policy Research analysis of 2011-2012 National Health Interview Survey (NHIS) and 2012 IPUMS American Community Survey (ACS).

FIGURE 6: Almost 70 percent of direct care workers in North Carolina lack access to earned paid sick days.



NOTE: Access rates are for individuals, 18 years and older, working in the private sector in North Carolina area regardless of their place of residence. Percentages and figures may not add to totals due to rounding. Source: Institute for Women’s Policy Research analysis of 2011–2012 National Health Interview Survey (NHIS) and 2012 IPUMS American Community Survey (ACS).

least likely to have access to paid family and medical leave, or longer-term paid leave.³³ The Family Medical Leave Act (FMLA) – the only existing law addressing workers’ need to take longer term leave – provides access to unpaid, job-protected leave to workers at companies with 50 or more employees who worked at least 1,250 hours in the preceding year.³⁴ Low-income workers, many of whom may have multiple part-time jobs and experience less job stability are less likely to be eligible under the federal law.

Even for those who are eligible under the FMLA, leave time is mostly unpaid. Research has shown that many low-income workers simply cannot afford to take longer-term unpaid time off, and even workers who can afford unpaid leave tend to take less leave time than what is offered, effectively limiting the impact of the policy.³⁵

Paid leave is not a perk. Both short-term and longer-term paid leave are a crucial piece of the caregiving puzzle for all caregivers, and especially for caregivers with limited economic security.

All caregivers need good jobs

Good jobs are jobs that allow families to maintain basic spending on necessities like food and doctor visits. Good jobs not only create a path to the middle class, they are essential for building thriving communities and economies. North Carolina is at a pivotal point in time as the need for care, and quality care, is increasing.

In addition to increased investment in services and supports for elderly residents and their caregivers (including access to Medicaid), a “good jobs” agenda is crucial to addressing our state’s care gap in a responsible and sustainable way.

- ★ **Good jobs pay a living wage.** Over 761,000 workers in North Carolina earn less than \$10.10 per hour, and approximately 130,000 of these workers bring home \$7.25 or less.³⁶ The inclusion of home health care workers under the protection of federal minimum wage and overtime laws was an important step and the implementation should be carefully monitored. However, for the thousands of workers currently working full-time and still only bringing home poverty-level wages, current minimum wage protections are insufficient.

As of January 2014, 21 states and the District of Columbia have minimum wages above the federal minimum wage. North Carolina HB 115/SB 220, introduced in the 2013 long session, would have been a first step in bringing North Carolina in line with other states’ efforts by indexing the minimum wage to inflation.³⁷ Although a joint resolution was introduced to allow the General Assembly to consider a minimum wage bill during the 2014 Joint Session, the proposal did not go forward. On the federal level, efforts to raise the federal minimum wage from \$7.25 to \$10.10 under the Fair Minimum Wage Act are stalled, but ongoing. Raising the low-wage floor – through state or federal legislation – would give low-wage workers in North Carolina a much-needed raise while boosting consumer spending in local economies.

- ★ **Good jobs pay earned wages.** Workers, at the very minimum, deserve to be paid their earned wages and to be free from wage theft. National data show that wage theft is rampant in low-wage industries. And, as noted previously, North Carolina low-wage industries (including home health) are overrepresented in the wage claims filed with the Wage and Hour Bureau of the NC Department of Labor.

North Carolina policy makers and agency heads should take action to make it easier for workers to make claims by increasing notification and posting requirements, increasing delinquent employers’ penalties, and strengthening enforcement by increasing resources for the Wage and Hour Bureau. HB 826, introduced in the 2013 long session, would have gone a long way toward doing just that, and in curbing this crime wave in North Carolina.³⁸

- ★ **Good jobs allow workers to take time to care for their family members.** For many workers, losing a day’s pay is as easy as catching a cold. Nearly half of North Carolina’s private-sector workforce lacks access to a single earned paid sick day and in the South Atlantic region only about one in 10 workers

have access to longer-term paid leave to help a family member recover from an illness or to welcome a new child.

The North Carolina Healthy Families and Workplaces Act (H100) – which would allow workers to accrue sick time at the rate of one hour for every 30 hours worked – has been re-introduced every session since 2008, but has not moved.³⁹ The North Carolina Caregiver Relief Act (H99), first introduced in 2011, would provide greater access to the federal FMLA by expanding the definition of “family” to include siblings, grandparents, grandchildren, stepchildren, stepparents, and parents-in-law. Similarly, this bill stalled in the 2013 long session.⁴⁰

Federal efforts to establish a paid leave insurance program through the FAMILY Act would address the major flaw in the only existing federal legislation that addresses work-family conflict, the Family Medical Leave Act. The FAMILY Act would provide eligible employees with up to 12 weeks of paid leave for their own serious illness, the serious illness of a child, parent or spouse, the birth or adoption of a child; or the injury of a family member in the military.⁴¹

Taking a child or a parent to a doctor’s appointment, recovering from an illness, or spending time to bond with a new born child – these are central and commonplace life events that shouldn’t put a workers’ job or a family’s economic security at risk. It’s about time. And it’s about economic security.

- ★ **Good jobs offer opportunity for advancement.** The opportunity for less-skilled workers to move up into higher skilled, higher-paid positions is a win-win for workers and employers. In the early 2000s, the North Carolina legislature stopped funding career pathway programs that had been established as part of welfare reform, but local workforce boards, nonprofit workforce intermediaries, and community-based organizations have picked up the mantle and have been experimenting with models targeted toward specific populations and industries. North Carolina has been recognized nationally for innovative programs targeting the direct care workforce.⁴²

Career pathways – as connected education and training programs with student support services – are effective tools for addressing the fundamental disconnect between industry demands and the labor market’s ability to provide it. Career pathways help workers attain mobility and provide employers with a skilled, dedicated workforce.

An economy that works for all depends on good jobs.

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10. Bureau of Labor Statistics, Occupational Employment Statistics: May 2013 Occupational Employment and Wage Estimates. The location quotient – or the ratio of the area concentration of occupational employment to the national average – is 1.99, which means that the occupation has a higher share of employment than average. Official figures may underestimate the size of this workforce for three primary reasons: often the defined occupations do not correspond directly to actual work; work that is performed through private arrangements may be unreported, and the publicly-employed workforce is not typically monitored. See PHI, <http://www.phinational.org/policy/states/data-sources>.
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33. One study found that workers living under the federal poverty level were more than two times as likely to provide significant hours of unpaid assistance to elderly parents as those above the poverty level. See Dodson, Lisa, Tiffany Manuel and Ellen Bravo, 2002. "Keeping Jobs and raising Families in Low-Income America: It Just Doesn't Work," Radcliffe Institute for Advanced Study.
34. 29 U.S.C. Section 2601
35. Houser, Linda and Thomas P. Vartanian, 2012. "Pay Matters: The Positive Economic Impacts of Paid Family Leave for Families, Businesses, and the Public," Center for Women and Work, Rutgers University. Public, Rutgers Center for Women and Work citing Han, W-J and Waldfogel, J, 2003. "Parental Leave: The Impact of Recent Legislation on Parents' Leave Taking," Demography, 40, 191-200
36. Bureau of Labor Statistics, 2013. "Minimum wage workers in North Carolina" and Economic Policy Institute analysis using Current Population Survey, Outgoing Rotation Group microdata
37. See NCGA SB 220/HB115 accessed at <http://www.ncga.state.nc.us/gascripts/BillLookUp/BillLookUp.pl?Session=2013&BillID=sb220&submitButton=Go>
38. See NCGA HB 826 accessed at <http://www.ncga.state.nc.us/gascripts/BillLookUp/BillLookUp.pl?Session=2013&BillID=H826>
39. See NCGA HB100/SB536 accessed at <http://www.ncga.state.nc.us/gascripts/BillLookUp/BillLookUp.pl?Session=2013&BillID=h100&submitButton=Go>
40. See NCGA HB99/S535 accessed at <http://www.ncga.state.nc.us/gascripts/BillLookUp/BillLookUp.pl?Session=2013&BillID=h99&submitButton=Go>
41. See National Partnership for Women and Families, 2013. "The Case for a National Family and Medical Leave Insurance Program (The FAMILY Act).
42. For example, WIN A STEP UP was an initiative aiming to enhance care in nursing homes by addressing nurse aide turnover. The program aimed to improve skills and increase career commitment. NC NOVA has also been recognized as a model as a special licensure program aimed at improving direct care jobs, reducing turnover, and improving quality care. See Harmuth, Susan and Thomas R. Konrad, 2010. "Strengthening the Direct Care Workforce in North Carolina," NC Medical Journal.



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