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"21st Century Caregiving: Supporting Workers, Family Caregivers, Seniors and People with Disabilities"

Introduction

Chairman Casey, Ranking Member Scott, and Members of the Committee, thank you for the opportunity to testify on the importance of investments in Medicaid's Home and Community-based Services as central to our economic recovery.

My name is Ai-jen Poo, and I am the Executive Director of the National Domestic Workers Alliance (NDWA) and Caring Across Generations (CAG). Founded in 2007, the National Domestic Workers Alliance is the nation's leading voice for 2.2 million domestic workers who work as nannies, home care workers, and house cleaners in private homes. NDWA works to improve the quality of jobs in the care economy, and to achieve fairness and dignity for this workforce that provides essential care and cleaning services in our homes. Many domestic workers are also older women, and family caregivers. NDWA's community includes over 250,000 domestic workers in all 50 states, and 74 local affiliate organizations and chapters in 36 cities and 19 states.

Caring Across Generations was founded in 2011 to bring together family caregivers, care workers, people with disabilities and older Americans to advocate for a strong care infrastructure that would support us all to live, work, care and age with dignity. Caring Across Generations is working to create a culture that values care and caregiving, and policies that support universal access to long-term services and supports (LTSS), childcare, paid family and medical leave (PFML) benefits and a strong care workforce. We work with a diverse network of over 100 national, state and local advocacy organizations and unions, including caregiver, aging, disability rights and justice, disease-based groups, women's organizations and more.

Together, NDWA and Caring Across Generations have worked for a decade to bring attention to the growing need for care, and the urgency of investing in Medicaid Home and Community Based Services for older adults and people with disabilities. I believe we have a once in a generation opportunity to do precisely that -- to build the 21st century care infrastructure we need.

Caregiving is personal to me. My grandfather, Liang Shao Pu, played a critical role in raising me. He lived a long and full life. He was a student and teacher of tai chi, a die-hard Wheel of

Fortune fan, and an avid reader. He spent a lifetime working and caring for his family, including his wife of more than 40 years after she suffered a stroke. Towards the end of his 93 years, he lost his eyesight, and needed more support than my family was able to provide him at home. We could not find appropriate home care support, so my grandfather was placed in a nursing home against his wishes.

I visited him there and I will not forget it. He was in bed in a dark room with six other people, including several who cried out in misery. The lights didn't work. My grandfather was distressed, he had not eaten or slept in some time, he was frightened, and depressed. A shell of himself. The staff was overworked and struggling to manage all the people in their care. After just three months in the facility, my grandfather passed away. I will always regret that these were the conditions of my grandfather's final days.

The Case for Robust Investments in Home and Community Based Services

While this story is my own, it is hardly unique. Eighty eight percent of aging adults prefer to receive long-term supports and services (LTTS) in home and community-based settings. But these services are out of reach for too many. Across the United States nearly 820,000 aging individuals and people with a disabilities are on waiting lists for Medicaid HCBS¹. People on waiting lists for Medicaid HCBS often wait years, sometimes decades to access these vital services. And we are facing an elder boom: by 2050, the population of people 65 and older will nearly double². With 10,000 people aging into retirement per day, and living longer, there's overwhelming demand for care in the home³.

For older Americans to live and age at home, we need infrastructure -- including a robust workforce that can meet the demand. From 2018 to 2028, the U.S. will need to fill over 4.4 million home care job openings -- making home care one of the fastest growing occupations in our economy. But because of low-wages and poor job quality, workers must struggle to survive in this profession. According to PHI, home care workers earn on average \$17, 200 annually. The median hourly wage for home care workers only increased by a total of 91 cents between 2009 and 2019⁵. In the same time period, the number of jobs in this industry saw growth of over

¹ MaryBeth Masumeci, Molly O'Malley Watts, and Priya Chidambraram. <u>Key State and Policy Choices about Medicaid Home and Community-Based Services</u> (February 4, 2020) available at https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/

² U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, What is the lifetime risk of needing and receiving long-term services and supports (April 4, 2019) available at https://aspe.hhs.gov/basic-report/what-lifetime-risk-needing-and-receiving-long-term-services-and-supports

³ Emily Swanson and Ricardo Alonso-Zaldivar. The Christian Science Monitor "Most Americans would rather age at home, says poll" (May 3, 2021) available at https://www.csmonitor.com/USA/Society/2021/0503/Most-Americans-would-rather-age-at-home-says-poll

⁴PHI, High Demand Yet Low Wages for Direct Care Workers available at https://phinational.org/news/new-research-high-demand-yet-low-wages-for-direct-care-workers/

⁵ PHI, Direct Care Worker Median Hourly Wages Adjusted for Inflation, 2009 to 2019 available at http://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Wage+Trends

1,400,000 jobs or approximately 145%. The wages have not kept pace with increases in cost of living over the last 10 years. As a result, one in eight direct care workers lives in poverty, and three-quarters earn less than the <u>living</u> wage in their states.

Care work is also emotionally taxing and physically punishing -- involving heavy lifting, long hours, and exposure to potentially hazardous materials¹⁰. Low pay, combined with difficult and poor working conditions, has led to chronic staffing shortages in the home care sector, and instability for care workers and the families that they serve.¹¹ Turnover rates are high¹². Even home care workers who love their jobs often leave the profession for other low-wage service jobs because they can't make ends meet on the wages they earn. For example, PHI found that in all 50 states and the District of Columbia, wages of direct care workers are lower than the median wage for other occupations with similar entry-level requirements, such as janitors, retail workers, and customer service representatives.¹³ This also means there are many parts of the country with home care deserts, where people simply cannot get access to these services because there's no workforce, especially in rural communities.

⁶ PHI, Direct Care Worker Employment, 2009 to 2019, available at http://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Employment+Trends

⁷ Bureau of Labor Statistics, Consumer Price Index Historical Tables for U.S. City Average, available at https://www.bls.gov/regions/mid-atlantic/data/consumerpriceindexhistorical_us_table.htm, See also Irene Jiang, Business Insider, How much American grocery staples like bread, bacon, and coffee cost now versus 10 years ago (Dec. 18, 2019) available at https://www.businessinsider.com/grocery-price-change-bread-bacon-cost-10-years-ago-now-2019-12#tomatoes-11. See also Aimee Picchi, CBS News, It's been a record 11 years since the last increase in U.S. minimum wage (Jul. 24, 2020) available at https://www.cbsnews.com/news/minimum-wage-no-increases-11-years/

⁸ Christian Weller, Beth Almeida, Marc Cohen, and Robyn Stone. Leading Age. "Making Care Work Pay: How Paying at Least a Living Wage to Direct Care Workers Could Benefit Care Recipients, Workers, and Communities" (September 2020) available at https://www.ltsscenter.org/wp-content/uploads/2020/09/Making-Care-Work-Pay-Report-FINAL.pdf

⁹ Christian Weller, Beth Almeida, Marc Cohen, and Robyn Stone. Health Affairs. "Making Care Work Pay: How Paying at Least a Living Wage to Direct Care Workers Could Benefit Care Recipients, Workers, and Communities" (December 7, 2020) available at https://www.healthaffairs.org/do/10.1377/hblog20201202.443239/full/

¹⁰Linda Burnham and Nik Theodore, Home Economics: The Invisible and Unregulated World of Domestic Work, National Domestic Workers Alliance, pp. 28-32 (2012) https://domesticworkers.org/sites/default/files/HomeEconomicsReport.pdf

¹¹ Chris Farrell, Forbes, The Shortage Of Home Care Workers: Worse Than You Think (April 18, 2019), available at https://www.forbes.com/sites/nextavenue/2018/04/18/the-shortage-of-home-care-workers-worse-than-you-think/?sh=6f1ed6f83ddd

¹² Margaret Barthiel, NPR, Many Health Workers Earned Low Wages, Suffered Losses During The Pandemic (March 10, 2021) available at https://www.npr.org/local/305/2021/03/10/975626535/many-health-workers-earned-low-wages-suffered-losses-during-the-pandemic

¹³ Robert Espinoza, PHI, Competitive Disadvantage: Direct Care Wages Are Lagging Behind (Oct. 13. 2020) available at https://phinational.org/resource/competitive-disadvantage-direct-care-wages-are-lagging-behind/

The President's proposed \$400 billion investment in Medicaid's Home and Community-based Services (HCBS) would expand access to these essential services and care for the older adults and people with disabilities. Medicaid eligible older adults and people with disabilities will finally have the services and supports they need to live independently and in their chosen community. And it will raise wages and improve conditions for the direct care workforce, an essential workforce in need of investment. These two goals are interdependent and we must invest boldly if we are to achieve these dual goals.

These investments would be historic and impactful for our recovery in several ways. First, according to a recent analysis, investing \$400 billion in the HCBS sector will create over 1.1 million new jobs each year over 10 years, nearly 800,000 of which are home and community-based care jobs. This investment would add an estimated \$40 billion additional income for workers and their families each year¹⁴. These figures include over 58,000 new jobs in Pennsylvania, over 18,000 in Arizona, and more than 14,000 jobs in Georgia to name a few. This proposed investment would generate \$40 billion per year in additional income for American families and the economy.

An investment in HCBS prioritizes a workforce that -- because of racism -- has faced exclusion from labor rights and protections since the New Deal¹⁵. To this day, 63% of home care workers are Black, Hispanic, Asian American/Pacific Islander or Native American.¹⁶ Placing this workforce, at the forefront of this jobs and infrastructure plan is not only good policy, it reflects a true commitment to equity. This investment will have compounded impacts for women, older women, and women of color -- seeding an economic recovery for women that is sorely needed. These are jobs that won't be automated, and can't be outsourced, so they will be here to stay, and we must make them good jobs. Just like we transformed manufacturing jobs in the 1920s and 1930s from dangerous, poverty wage jobs, to jobs with real economic mobility, we can and must do the same for care jobs. And we will all benefit.

Second, more than 50 million unpaid family caregivers are stepping in and juggling care for their loved ones while also managing full-time work outside the home. We know that 60 percent of family caregivers are women. The majority of working family caregivers report having to make changes to their work status due to caregiving responsibilities, like reducing work hours,

https://www.peri.umass.edu/component/k2/item/1465-the-economic-effects-of-investing-in-quality-care-jobs-and-paid-family-and-medical-leave

¹⁴Lenore Pallodino, Chirag Lala. Political Economy Research Institute. "The Economic Effects of Investing in Quality Care Jobs and Paid Family and Medical Leave" (June 14, 2021) available at

¹⁵ Economic Policy Institute, Domestic workers are underpaid and unprotected by labor law during the coronavirus pandemic (May 14, 2020) available at https://www.epi.org/press/domestic-workers-are-underpaid-and-under-protected-by-labor-law-during-the-coronavirus-pandemic/

¹⁶ Christian Weller, Beth Almeida, Marc Cohen, and Robyn Stone, Leading Age, Making Care Work Pay, p. 13 (Sept. 2020) available

at https://leadingage.org/sites/default/files/Making%20Care%20Work%20Pay%20Report.pdf

changing jobs, or leaving the workforce altogether¹⁷. The burden is especially acute for sandwich generation family caregivers, the 11 million Americans providing care for an aging or disabled loved one while also raising and managing caring for children.¹⁸ This is particularly important in light of the nearly 3 million women who've been pushed out of the workforce in the pandemic because of caregiving challenges, also disproportionately women of color. Women's overall participation in the workforce dropped to 57% -- the lowest level since 1988¹⁹. When family caregivers are forced out of the labor market, there are both short term and long-term consequences for their financial well-being, including diminished Social Security benefits.

Third, the benefit to consumers cannot be overstated. Quality of life and independence for older people and people with disabilities should be a top priority for an aging nation. Consistent, dependable assistance allows people to live full lives, with dignity, connected to their families and communities. Atul Gawande writes in his bestselling book, *Being Mortal*, about the importance of "being the author of your own story." These services allow people to live life on their own terms, even as they become more frail, they allow people with disabilities to work and be full participants in our recovery and so much more.

Finally, there are benefits to our public health and our health care system overall. The direct care workforce provides critical support with activities of daily living such as bathing, dressing, and some also provide medical care, such as managing medications or performing tracheostomy care. Improving and expanding these services in the home and community will result in downstream savings in our healthcare system, reducing the need for institutional care, which can be more expensive, and preventing expensive, unnecessary emergency room visits and rehospitalizations.

Conclusion and Recommendations

The care economy is the foundation of the entire economy. When we invest in it, we invest in jobs and prosperity for all. That is why Medicaid Home and Community Based Services are widely popular across the political spectrum, across the country. Voters and families agree -- we need a strong care infrastructure. And these services, and this workforce, are simply essential.

We have a once in a generation opportunity to strengthen our economy for the next era, an opportunity that is also a responsibility we have to our nation's older people, people with disabilities, our families and the caregiving workforce.

¹⁷ National Alliance for Caregiving. "Caregiving in the U.S. 2020" (2020) available at https://www.caregiving.org/caregiving-in-the-us-2020/

¹⁸Lisa Weber Raley, MA. Burning the Candle at Both Ends: Sandwich Generation Caregiving. In the U.S. (November 2019) available at https://caringacross.org/wp-content/uploads/2019/11/NAC SandwichCaregiving Report digital 112019.pdf

¹⁹ National Women's Law Center, The Pandemic, The Economy, & The Value of Women's Work p. 3 (March 2021) available at https://nwlc.org/wp-content/uploads/2021/03/Final NWLC Press CovidStats.pdf

Former First Lady Rosalynn Carter once said, "There are only four kinds of people in the world. People who are caregivers or will be caregivers. People who need care or will need care." We will all be in a position of providing or needing care, sometimes simultaneously, particularly because our nation is aging.

The proposed investment of \$400 billion in the American Jobs Plan is an investment in all of us, one that cannot be shortchanged. The additional investments in child care and paid family and medical leave in the American Families Plan, these are investments in us -- in our ability to live, work and care, with dignity, even as we age.