

# The Urgent Need to Better Support Home- and Community-Based Services During the COVID-19 Pandemic: A Call to Action for State Advocates

Under the newly enacted American Rescue Plan,<sup>1</sup> states can receive increased Medicaid funding from the federal government from April 1, 2021, through March 31, 2022, to “enhance, expand, or strengthen” home- and community-based services (HCBS). Specifically, states can claim a 10% increase in federal Medicaid matching funds for such enhancements.<sup>2</sup>

HCBS is an essential component of our health care system that allows adults (including the growing senior population) and children with disabilities or complex medical needs to live at home or in home-like settings instead of institutions. Services include home health care, personal care, case management, adult day health, habilitative and rehabilitative services, among others. Although state Medicaid programs must cover home health, other HCBS are covered at state option or through waiver programs that are subject to caps. In fiscal year 2018, about 4.8 million people received Medicaid-funded HCBS, but waiting times for such services provided through waiver programs averaged 39 months.<sup>3</sup> Home- and community-based care settings can provide a safe alternative to long-term care facilities, where COVID-19 has raged and caused many deaths. The direct care workers\* who provide HCBS are critical to our country’s aging adults and people with disabilities each and every day, but policymakers often overlook and ignore their needs.

\*We use the term *direct care worker* to refer to workers who provide one-on-one care in the home and/or in community settings, except when the source cited specifically refers to *home care workers*.

## 5 Recommendations to Urge Your State to Pursue:

1. States should increase the availability of HCBS and reduce waiting lists for those services.
2. States should provide vaccination outreach to both direct care workers and people who rely on home- and community-based care.
3. States should enhance the safety of direct care workers, and of seniors and people with disabilities who use HCBS, by providing personal protective equipment and sick leave.
4. States should pay equitable wages to workers who provide HCBS, both through the wage scales states set directly and through contract provisions with home care agencies.
5. States should provide for appropriate training to direct care workers and should undertake larger initiatives to provide for professional growth and advancement.

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### **States must take action to meet growing needs for home- and community-based care**

The current demand for HCBS is partially driven by the transition of care from institutional settings to home- and community-based settings — a need that has become more acute during the COVID-19 pandemic. News outlets have highlighted the number of deaths in nursing home settings. This devastating reality is one reason why nursing home occupancy rates decreased in 2020. In Connecticut, for example, nursing home occupancy rates dropped 14 percentage points between March and September of 2020, and the nursing home industry lost jobs, while home health services employment opportunities increased dramatically.<sup>4</sup>

Medicaid-funded HCBS can be provided in two broad ways: through Medicaid waivers that sometimes cap the number of people served, or as “regular” Medicaid state plan benefits. Both types of Medicaid benefits have inadequate capacity in most states. There is clear evidence of unmet need for Medicaid-funded HCBS.

- » The Kaiser Family Foundation found that 40 states had waiting lists for services under home- and community-based services waivers in 2017 and the number of people on waiting lists had increased steadily over the last 15 years.<sup>5</sup>

- » Medicaid-funded HCBS agencies struggle to recruit enough qualified direct care workers to serve the populations that require their services.<sup>6</sup>
- » A June 2020 survey of home health agencies in the District of Columbia showed that nearly three-fourths of them were losing aides, and more than half the agencies could not provide all their patients with direct care workers on every shift. Agencies reported that many direct care workers were afraid to work during the COVID-19 pandemic; faced difficulties getting child care, transportation to work, and protective equipment; and that the “risk of the work does not justify the reward.”<sup>7</sup>

### **During the COVID-19 pandemic, states should take action to improve the health and safety of home- and community-based care workers and people who depend on their services**

Direct care workers who provide HCBS are experiencing difficulties similar to those that have impacted health care workers and nursing home workers across the United States. These direct care workers are at unique risk because they must maintain close proximity while caring for patients within home- and community-based settings. Because it is impossible for direct care workers to provide care while maintaining a distance, they must have access

to proper protection and testing. Despite these challenges, direct care workers are consistently underpaid and under-supported. State Medicaid programs contract with agencies that employ some direct care workers, and Medicaid may pay other workers who provide home- and community-based care as independent contractors; unfortunately, in both cases, wages and benefits are generally inadequate.

Historically low pay for home- and community-based care disadvantages a workforce that is composed mainly of Black and Latina women.

- » Almost one in nine (87%) of home care workers in the United States are women, and 51% of home care workers are Black, Hispanic, or Latino.<sup>8</sup> Immigrants make up 31% of the home care workforce, and approximately 40% of these workers do not speak proficient English.<sup>9</sup>
- » The median hourly wage of home care workers is \$12.15, with median annual earnings of \$25,280. On average, the lower 10% of home care workers earn only \$19,430 annually, while the top 10% earn \$34,180 annually.<sup>10</sup>
- » Approximately 38% of home care workers work part-time, often because of inconsistent demand and pay.<sup>11</sup> Low hourly and annual wages do not allow home care workers to commit to full-time schedules, and many of these workers must work at least one other job to support their households.<sup>12</sup>
- » An April 2020 study on what home care workers face amid the pandemic in New York City<sup>13</sup> found that they did not receive training on the virus, although they were tasked with screening patients for symptoms, and that their employers

did not provide them with masks, gloves, and other personal protective equipment. Instead, workers spend their own money or rely on family and friends to purchase personal protective equipment for them.

- » Throughout the pandemic, many home- and community-based care workers have been unable to utilize paid sick leave because the benefit scarcely exists for these workers. The Families First Coronavirus Response Act guaranteed eligible workers up to 80 hours of paid leave for health concerns from coronavirus. However, 18 million health care workers were not guaranteed leave under this law due to exclusion or exemption at their employers' discretion.<sup>14</sup>

## How Could the American Rescue Plan Funding Help?

The American Rescue Plan Act temporarily increases federal Medicaid matching funds for states to make improvements to their HCBS programs. Under the American Rescue Plan, the federal government will increase its matching rate by 10 percentage points for enhancements to HCBS provided under state plan amendments or through waivers.<sup>15</sup> The increased match can apply to home health care, personal care, Programs of All-Inclusive Care for the Elderly (PACE), home- and community-based supports, case management, and rehabilitation services.

### 1. Increasing available services

The American Rescue Plan Act (Section 9817) provides increased federal matching funds that state Medicaid programs could use to reduce waiting lists and enhance home health, personal care, PACE, and home- and community-based services from April 2021 through March 2022.<sup>16</sup> States could use the additional funds to help

people transition from institutional settings or shelters to home- and community-based settings and to pay expenses such as initial rent and food purchases to help people settle into their homes. Many states have already used emergency waiver authority under Section 1115, Section 1315, and Section 1915(c), Appendix K, to provide home- and community-based care in alternative settings, pay higher rates to direct care workers to maintain home- and community-based care capacity, and ease the application process for home- and community-based care during the pandemic. Kaiser Family Foundation provides tables listing these state emergency actions, and the Center for Medicaid and Medicaid Services provides further information.<sup>17</sup>

States could also increase service limits in their Medicaid HCBS programs. Most states place strict limits on hours per week of direct care that often impact the quality of life of beneficiaries in stark ways.<sup>18</sup> These limits should be a priority target for advocates as states determine how to utilize American Rescue Plan funds.

## 2. **Prioritizing vaccinations**

Both people who use HCBS and direct care workers are at high risk and ought to be at the highest priority level for vaccination. Some states and localities have stepped up to provide homebound people with vaccinations at home, or to provide Medicaid-funded transportation to vaccination appointments.<sup>19</sup> States such as Oregon and New York have included home- and community-based care workers in the 1A group of frontline health care workers who will be vaccinated first. The Service Employees International Union has provided targeted information to direct care

workers via the internet, social media, and town halls, and by co-hosting vaccination clinics.<sup>20</sup> But in many states, government websites do not clearly explain whether home- and community-based care workers are considered frontline health workers who may receive vaccinations on a priority basis. In many areas, scheduling vaccination appointments requires time-consuming telephone calls or computer searches. Moreover, lack of transportation to vaccination sites may be a barrier for both direct care workers and the seniors and people with disabilities whom they serve. States could help direct care workers receive vaccinations at the same time as the people they serve. The American Rescue Plan provides further federal and state funding for vaccination distribution and outreach, and advocates can continue to devise ways to optimize vaccination programs.

## 3. **Providing personal protective equipment and sick leave**

The provision of paid sick leave for direct care workers has largely depended on union advocacy, leaving nonunionized workers and their patients at obvious risk in many states.<sup>21, 22</sup> The American Rescue Plan provides enhanced funding that state Medicaid programs and public health agencies could use for emergency supplies and equipment to protect home- and community-based care workers. The tax credits that the plan provides to employers that offer paid sick leave may encourage home care agencies to provide paid sick leave for direct support workers. State Medicaid agencies could also require contracted home care agencies to provide sick leave for their workers — and could conceivably claim enhanced Medicaid matching funds for the provision of sick leave as

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an enhancement to HCBS providers. Similarly, states should plan to extend sick leave and provide protective equipment to independent providers of home- and community-based care.

#### **4. Offering increased wages and professional advancement for direct care workers**

State Medicaid programs could use increased matching rates for HCBS enhancements under the American Rescue Plan to increase compensation to direct care workers during the pandemic. States can increase direct care workers' wages through several mechanisms, helping workers paid as independent contractors and those that work through agencies. They can use minimum wage laws, negotiate contracts with the unions of direct care workers, and/or require a minimum rate of pay in contracts with home- and community-based care provider agencies. States like Virginia and Massachusetts have leveraged previous rounds of COVID-19 federal funding to support special hazard pay for HCBS workers.<sup>23, 24</sup>

#### **5. The American Rescue Plan can also help states pay for training the HCBS workforce regarding COVID-19 care**

Enhancing the ability of direct care workers and their patients to address this public health emergency is one step toward the larger goal of ongoing, advanced skills training. There are good examples from New York and California of formalized advancement programs for direct care workers.<sup>25, 26</sup>

### **Call to Action for State Advocates**

The examples described above demonstrate that some states have made progress toward overcoming challenges experienced by people who need HCBS, and the direct care workers who serve them, even amid the pandemic. Enhanced federal funding can enable many more states to address inequities experienced by direct care workers, seniors, children with complex medical needs, and others with disabilities throughout the United States. Advocates should urge their states to quickly take up the enhanced match for Medicaid HCBS, provided until March 31, 2022 under Section 9817 of the American Rescue Plan Act, to improve conditions for direct care workers and the people who rely on their services. It will also be important for advocates to monitor the measures their states take to improve services and inform policymakers of their recommendations for permanent solutions.

In order to create an equitable, stable and reliable home care workforce, state advocates should call for federal and state policymakers to permanently expand funding under Medicaid for states' HCBS programs, expand access to services to account for increased need, raise wages for direct care workers, distribute personal protective equipment to direct care workers across the United States, provide appropriate safety measures in home- and community-based settings whenever new health threats emerge, ensure sick leave for direct care workers across the United States, and develop a well-trained workforce.

## Endnotes

- <sup>1</sup> American Rescue Plan, Public Law 117-2, HR 1319. <https://www.congress.gov/bill/117th-congress/house-bill/1319/text/pl?overview=closed>
- <sup>2</sup> American Rescue Plan, Section 9817. The additional 10% Federal Medical Assistance Percentage is up to a ceiling of 95% Federal Medical Assistance Percentage .
- <sup>3</sup> Kaiser Family Foundation. 2020. Key state policy choices about Medicaid home and community-based services. Washington, D.C.: Kaiser Family Foundation. <https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/>
- <sup>4</sup> L. Klein, “Demand for home health care surges amid COVID-19, shifting industry landscape” (Hartford, Connecticut: Hartford Business Journal, November 16, 2020). <https://www.hartfordbusiness.com/article/demand-for-home-health-care-surges-amid-covid-19-shifting-industry-landscape>
- <sup>5</sup> M. Musumeci, P. Chidambaram, and M. O’Malley Watts, “Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists.” Kaiser Family Foundation, April 4 2019. <https://www.kff.org/medicaid/issue-brief/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists/>
- <sup>6</sup> A. Donlan, “In-Home Care Providers Must ‘Keep Pedal Down on Recruitment’ Amid COVID-19 Crisis,” *Home Health Care News*, April 2, 2020.
- <sup>7</sup> S. Brown, N. Richardson, and C. Schlosberg, “COVID-19 Impact on Home Health Aides Survey Results” (D.C. Coalition on Long Term Care and D.C. Appleseed, January 2021, slide presentation). <https://www.dclongtermcare.org/wp-content/uploads/2021/01/COVID-19-Impact-on-HHAs-Survey-Results.pdf>.
- <sup>8</sup> Paraprofessional Healthcare Institute, “U.S. Home Care Workers: Key Facts,” <https://phinational.org/resource/u-s-home-care-workers-key-facts-2019/>
- <sup>9</sup> Ibid.
- <sup>10</sup> Bureau of Labor Statistics, U.S. Department of Labor, *Occupational Outlook Handbook, Home Health and Personal Care Aides*. <https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm>
- <sup>11</sup> Paraprofessional Healthcare Institute, Op cit.
- <sup>12</sup> Paraprofessional Healthcare Institute, Op. cit.
- <sup>13</sup> T. A. Allison, A. Oh, and K. L. Harrison, “Extreme Vulnerability of Home Care Workers During the COVID-19 Pandemic – A Call to Action,” *JAMA Intern Med.* 2020;180(11):1459–1460. (August 4, 2020). doi:10.1001/jamainternmed.2020.3937.
- <sup>14</sup> M. Long and M. Rae, “Gaps in the Emergency Paid Sick Leave Law for Health Care Workers” (San Francisco, California: Kaiser Family Foundation, June 17, 2020). <https://www.kff.org/coronavirus-covid-19/issue-brief/gaps-in-emergency-paid-sick-leave-law-for-health-care-workers/>
- <sup>15</sup> The enhanced match would apply to home- and community-based services, including “money-follows-the-person” programs, provided under Sections 1902, 1915, and 1937 of the Social Security Act and to Section 1115 Demonstration Programs.
- <sup>16</sup> American Rescue Plan Act of 2021, op cit.
- <sup>17</sup> <https://www.kff.org/coronavirus-covid-19/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/>; Centers for Medicare and Medicaid Services, Emergency Preparedness and Response for Home and Community Based 1915(c) Waivers, Approved COVID-19 Appendix K documents. <https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html>, as of March 26, 2021. To provide just two of many examples from the Appendix K documents, during the pandemic, Alaska is providing more services in private homes, allowing family members to be paid as direct service workers, and increasing payment for home- and community-based care; and Colorado is providing home- and community-based services to children and adults with disabilities in private homes, extended family homes, hotels, and paid lodgings.
- <sup>18</sup> Musumeci, et al., op cit. <https://www.kff.org/report-section/key-state-policy-choices-about-medicaid-home-and-community-based-services-issue-brief/>
- <sup>19</sup> J. Bergal, “Without a Ride, Many in Need Have No Shot at COVID-19 Vaccine,” *Stateline*, Pew, February 1, 2021. <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2021/02/01/without-a-ride-many-in-need-have-no-shot-at-covid-19-vaccine>
- <sup>20</sup> SEIU 503, “COVID-19 Vaccine and Resources,” March 20, 2021. [https://seiu503.org/member\\_news/covid-19-vaccine-information-resources/](https://seiu503.org/member_news/covid-19-vaccine-information-resources/) and Nich Reisman, “Hospice, Home Care Workers Eligible for COVID-19 Vaccine Next Week,” *Spectrum News*, January 4, 2021. <https://spectrumlocalnews.com/nys/central-ny/ny-state-of-politics/2021/01/04/hospice--home-care-workers-eligible-for-covid-19-vaccine-next-week>
- <sup>21</sup> In May 2020, the United Domestic Workers (UDW) of AFSCME was



one of the unions involved in securing emergency services for union members, including PPE, up to two weeks of emergency paid sick leave, an emergency provider backup system so patients can receive care when their usual home care worker is sick, and temporary unemployment insurance for home care workers caring for a child or spouse. UDWA.org, “UDW secures emergency victories for IHSS providers and our families,” May 19, 2020. <http://www.udwa.org/2020/05/udw-secures-emergency-victories-for-ihss-providers-and-our-families/>

<sup>22</sup> A. Knevich, “They serve the vulnerable, but many low-wage home care workers overlooked in pandemic, Baltimore area advocates say,” *Baltimore Sun*, June 8, 2020.

<https://www.baltimoresun.com/coronavirus/bs-md-home-health-aides-pandemic-20200608-mdksudv3qjg6hptnhpbtjrwqu-story.html>

<sup>23</sup> On October 15, 2020, Virginia Governor Ralph Northam authorized \$73 million from federal Coronavirus Aid, Recovery, and Economic Security (CARES) Act funding (available to states through December 2020, but now expired) to provide hazard pay to home health personal care attendants who served vulnerable populations during the pandemic. This provided one-time payments of \$1,500 to 43,500 home health workers who served Medicaid recipients in Virginia between March 12 and June 30, 2020. Additionally, Virginia approved

Thanks to Amber Christ, Justice in Aging, and Sarah Nolan, SEIU, for their review of an early draft of this paper.

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<sup>24</sup> In 2021, Massachusetts’ 1199 SEIU United Healthcare Workers East members will receive regular raises that will increase their hourly wages to \$16.10. This victory increases the \$15 minimum wage that was established in their last contract. In addition to increased wages, this contract victory included 50 hours of paid time off for home care workers annually and expanded opportunities for training and education. Seiu.org, “Massachusetts home care workers, Gov. Baker celebrate new standard-setting contract,” <https://www.seiu.org/blog/2019/8/massachusetts-home-care-workers-gov-baker-celebrate-new-standard-setting-contract#:~:text=Home%20care%20workers%20from%20across,wages%20to%20%2416.10%20in%202021>

<sup>25</sup> The Paraprofessional Healthcare Institute’s Care Connection project provides one example of the development of advanced roles for home care workers. In 2014, the New York State Department of Health-funded program created an advanced role for home care workers, called Care Connections Senior Aides, with training that enhanced home care workers’ “observation and documentation skills, [taught them] how to effectively offer other home care workers supporting and education, and [deepened] their knowledge of chronic diseases.” In addition to a greater sense of value felt by these senior aides, they received a 60% wage increase that translated to an approximate increase of \$11,000 annually. Phinational.org, “Care Connections,” [https://phinational.org/case\\_study/care-connections/](https://phinational.org/case_study/care-connections/)

<sup>26</sup> In California, a home care worker training program, delivered in multiple languages, has enhanced skills including communication, infection control, and dementia care and has contributed to a decline in patients’ repeat emergency department visits. Angelina Drake, “How ‘Upskilling’ Can Maximize Home Care Workers’ Contributions And Improve Serious Illness Care.” *Health Affairs*, March 4, 2019. <https://www.healthaffairs.org/doi/10.1377/hblog20190227420595/full/>

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