

2021

Retaining Medicaid COVID-19 Changes to Support Community Living

Elizabeth Edwards
edwards@healthlaw.org

David Machledt
machledt@healthlaw.org

Jennifer Lav
lav@healthlaw.org

Follow this and additional works at: <https://scholarship.law.slu.edu/jhlp>



Part of the [Health Law and Policy Commons](#)

Recommended Citation

Elizabeth Edwards, David Machledt & Jennifer Lav, *Retaining Medicaid COVID-19 Changes to Support Community Living*, 14 St. Louis U. J. Health L. & Pol'y (2021).

Available at: <https://scholarship.law.slu.edu/jhlp/vol14/iss2/10>

This Article is brought to you for free and open access by Scholarship Commons. It has been accepted for inclusion in Saint Louis University Journal of Health Law & Policy by an authorized editor of Scholarship Commons. For more information, please contact [Susie Lee](#).

RETAINING MEDICAID COVID-19 CHANGES TO SUPPORT COMMUNITY LIVING

ELIZABETH EDWARDS,* DAVID MACHLEDT** & JENNIFER LAV***

ABSTRACT

The impact of COVID-19 on people with disabilities in institutional settings, like nursing facilities, has garnered significant attention. But people receiving comparable services in the community have also been affected significantly. States used several emergency authorities in efforts to facilitate access to and stabilize these Medicaid home and community-based services (HCBS), including behavioral health services. Although states made different policy choices within those authorities, many states expanded the provider pool, increased HCBS provider rates, decreased onerous utilization controls and other barriers to care, expanded telehealth, and added new community-based services. These state policy responses have resulted in new services or HCBS delivery models that rely less on congregate services and reinforce the aims of Olmstead and the ADA. Converting some of the more effective emergency measures into permanent policy changes could improve health equity and help diminish longstanding legal and administrative barriers that hinder access to Medicaid-funded community-based services. While each Medicaid agency should evaluate which of these emergency policies will be beneficial for people with disabilities in their specific state, this Article identifies several strategies that present low risks to participants, improve workforce stability, and reduce health disparities. This Article encourages states to consider integrating such policies into their

* Elizabeth Edwards is a Senior Attorney at the National Health Law Program where she uses policy advocacy and litigation to improve access to community-based Medicaid services, ensure due process and the right to services, and address issues of bias in services. The authors would like to thank Fabiola Carrión and Héctor Hernández-Delgado for their valuable review and input as well as Kasey Nichols for research assistance.

** David Machledt is a Senior Policy Analyst at the National Health Law Program. where he focuses on improving health care access for people with disabilities, strengthening oversight and quality of care in Medicaid, and making care more equitable and affordable for underserved populations.

*** Jennifer Lav is a Senior Attorney at the National Health Law Program where she works on issues related to behavioral health, federal health care reform, Medicaid, and long term services and supports.

HCBS programs beyond the public health emergency to strengthen the HCBS service system and improve access to these critical services.

I. INTRODUCTION

COVID-19 has hit people with disabilities and their caregivers extremely hard. Morbidity and mortality rates for these individuals have been far higher than for the general population.¹ The pandemic increased stress on the critical Medicaid home and community-based services (HCBS) system, which helps keep people in the community, rather than in institutions.² Keeping people out of institutions has been especially important due to the high infection risk in many congregate settings.³ While the pandemic increased pressure on an already stressed HCBS system, associated Medicaid emergency-based flexibilities also drove some positive changes that facilitated access, shifted care away from congregate settings, and improved provider supports.⁴

The federal and state COVID-19 responses have unfolded in the context of long-standing structural biases in Medicaid that favor institutional long-term care, undervalue HCBS for people with disabilities and the people who support them, and perpetuate health disparities, including racial/ethnic disparities.⁵ Chronic under-resourcing of HCBS presents complex challenges for its providers and participants who face an elevated risk of exposure, additional needs for personal protective equipment (PPE), and significant staff shortages.⁶ The federal response to COVID-19 has justifiably directed additional needed Medicaid resources and guidance toward nursing facilities devastated by the

1. Daniel Young, *Black, Disabled, and Uncounted*, NAT'L HEALTH L. PROGRAM (Aug. 7, 2020), <https://healthlaw.org/black-disabled-and-uncounted/>.

2. Elizabeth Edwards, *Keep Essential Care: Home and Community-Based Care*, NAT'L HEALTH L. PROGRAM (Apr. 8, 2020), <https://healthlaw.org/keep-essential-care-home-and-community-based-care/>.

3. *Id.*

4. *Id.*

5. See, e.g., Robyn M. Powell, *Applying the Health Justice Framework to Address Health and Health Care Inequities Experienced by People with Disabilities During and After COVID-19*, 96 WASH. L. REV. 93, 104–14, 129 (2021) (discussing health and health care inequities for people with disabilities before and during COVID-19). Home and Community-Based Services (HCBS), as used in this Article, encompass services that help with activities of daily living, like bathing and dressing; services to support people in community activities like supported employment; and behavioral health services, including mental health and substance use disorder (SUD) services. Some use HCBS to refer to services typically targeted to individuals with developmental, intellectual, or physical disabilities. This Article uses a broader definition that encompasses the full array of services that support community living for people with various types of disabilities and help them live in their own homes and communities and avoid settings that are segregated from society. The Americans with Disabilities Act as amended in 2008 has an inclusive definition of disability, which includes individuals who are receiving treatment for SUD, although it excludes individuals who are currently using an illegal substance. 42 U.S.C. § 12102; ADA Amendments Act of 2008, Pub. L. 110-325, §2(a), 122 Stat. 3553 (2008); 28 C.F.R. § 35.131(a)(1).

6. Edwards, *supra* note 2.

pandemic.⁷ However, HCBS provides alternatives to institutional services and needs comparable attention.⁸

States have taken numerous emergency actions to stabilize HCBS provider availability, increase HCBS provider rates, and add new community-based services during the pandemic.⁹ Converting some of the more effective emergency measures into permanent policy changes could help diminish longstanding legal and administrative barriers that hinder access to Medicaid community-based services. A more robust and resilient community-based services infrastructure would allow people with disabilities to access the full benefits of community living both during and after an emergency.¹⁰ While some pandemic-based HCBS changes are appropriate only in the context of an emergency, evaluating the impact of those changes will help states respond to future emergencies.¹¹

This Article explores how the COVID-19 response has unfolded in the context of systemic inequities that have long hindered access to Medicaid HCBS. While some of the HCBS federal and state emergency policy changes have increased access to services and addressed longstanding barriers, others have likely exacerbated health inequities, particularly among Black, Indigenous, Asian American and Pacific Islander, and Latinx communities, and people with disabilities.¹² This Article details the most common emergency changes that

7. *COVID Relief Funding for Medicaid Providers*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N 4-7 (Feb. 2021), <https://www.macpac.gov/wp-content/uploads/2021/02/COVID-Relief-Funding-for-Medicaid-Providers.pdf> (describing funding targeted to nursing facilities, earlier funding to nursing facilities, and barriers faced by HCBS providers). *See also* T. Edelman & M. Edelman, *Nursing Facilities Have Received Billions of Dollars in Direct Financial and Non-Financial Support During Coronavirus Pandemic*, CTR. FOR MEDICARE ADVOCACY (Mar. 17, 2021), <https://medicareadvocacy.org/report-snf-financial-support-during-covid/>; Robert Holly, *HHS Sending \$25 Billion to Medicaid Providers, Safety Net Hospitals*, HOME HEALTH CARE NEWS (June 9, 2020), <https://homehealthcarenews.com/2020/06/hhs-sending-25-billion-to-medicaid-providers-safety-net-hospitals/> (discussing the wait for relief spending for Medicaid-only providers, which encompasses many Medicaid HCBS providers).

8. Starting April 1, 2021, more than 15 months after COVID-19 was declared a national public health emergency, states did become eligible to receive a one year increase in federal funding for HCBS as well. American Rescue Plan of 2021, Pub. L. No. 117-2.

9. *See generally* Elizabeth Edwards, *COVID-19 Changes to HCBS Using Appendix K: Approval Trends*, NAT'L HEALTH L. PROGRAM (Mar. 30, 2020), <https://healthlaw.org/resource/covid-19-changes-to-hcbs-using-appendix-k-approval-trends/>.

10. *See* MaryBeth Musumeci et al., *State Actions to Sustain Medicaid Long-Term Services and Supports During COVID-19*, KAISER FAM. FOUND. (Aug. 26, 2020), <https://www.kff.org/medicaid/issue-brief/state-actions-to-sustain-medicaid-long-term-services-and-supports-during-covid-19/>.

11. *See id.*

12. *Id.*; Richard A. Oppel Jr. et al., *The Fullest Look Yet at the Racial Inequity of Coronavirus*, N.Y. TIMES (July 5, 2020), <https://www.nytimes.com/interactive/2020/07/05/us/coronavirus-latinos-african-americans-cdc-data.html>.

states have implemented to improve access to care and reduce transmission risk during the public health emergency. Finally, this Article discusses how states should evaluate the efficacy of these policies, including their impact on health equity, as they consider making some of the pandemic-based changes permanent—a step which could help reduce the long-standing institutional bias in Medicaid and help people with disabilities of all ages enjoy the full benefits of community living.

II. COVID-19 IN THE CONTEXT OF EXISTING INSTITUTIONAL BIAS

A. Medicaid's Historic Institutional Bias

The COVID-19 pandemic has unfolded in a landscape of uneven coverage and resource allocation for long-term care. Medicaid pays for the majority of long-term services and supports for people with disabilities of all ages, including HCBS and institutional services.¹³ The Medicaid statute lays out basic federal requirements for program administration and a framework with mandatory and optional eligibility categories and services.¹⁴ States then have the flexibility to choose optional eligibility groups (e.g., allowing individuals to spend down to eligibility based on high medical expenses), adjust some income thresholds, elect optional services (e.g., dental, vision, prescription drugs), and to determine delivery systems (e.g., managed care or fee-for-service) and other program features.¹⁵

Medicaid's structure has always favored institutional care over HCBS.¹⁶ For example, institutional care in a nursing facility is a federally mandated service for adults, while comparable community-based services, including for behavioral health, are largely optional for states.¹⁷ States can choose to provide community-based services through a variety of mechanisms, including state plan services, Section 1915(c) waivers as alternatives to institutional care, Section

13. *Long Term Services & Supports*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/long-term-services-supports/index.html> (last visited Nov. 15, 2020).

14. *Federal Requirements and State Options: How States Exercise Flexibility Under a Medicaid State Plan*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N 1 (Aug. 2018), <https://www.macpac.gov/wp-content/uploads/2017/03/Federal-Medicaid-Requirements-and-State-Options-How-States-Exercise-Flexibility-Under-a-State-Plan.pdf> [hereinafter MACPAC].

15. *Id.* at 2–3.

16. NGA T. THACH & JOSHUA M. WIENER, OFF. OF DISABILITY, AGING & LONG-TERM CARE POL'Y, U.S. DEP'T OF HEALTH & HUM. SERVS., AN OVERVIEW OF LONG-TERM SERVICES AND SUPPORTS AND MEDICAID: FINAL REPORT 1 (2018).

17. MaryBeth Musumeci et al., *Key State Policy Choices About Medicaid Home and Community-Based Services*, KAISER FAM. FOUND. 10 (2020), <http://files.kff.org/attachment/Issue-Brief-Key-State-Policy-Choices-About-Medicaid-Home-and-Community-Based-Services>. When a state participates in Medicaid, it must provide a prescribed array of mandatory benefits and then may add optional benefits to its program. Therefore, while very few Medicaid programs look alike across the states, they all have a core set of mandatory services. MACPAC, *supra* note 14.

1915(i) and 1915(k) state plan community-based services, and through Section 1115 demonstration programs.¹⁸ Optional 1915(c) waivers are commonly used by states as alternatives to institutional care, like in a nursing facility or an intermediate care facility for individuals with intellectual disabilities (or related conditions) (ICF-IID).¹⁹ Unlike other Medicaid eligibility pathways, 1915(c) waivers allow states to target specific populations and cap enrollment, which often leads to long waitlists.²⁰ States have long set strict service limits or simply not covered some optional HCBS, including behavioral and mental health treatments.²¹

Provider capacity issues have also limited state HCBS programs. States have struggled to maintain sufficient HCBS direct care workers to support the growing demand for HCBS.²² Direct care workers generally work for low wages and limited benefits, conditions that have contributed to chronic HCBS provider

18. Musumeci et al., *supra* note 17. While states are not mandated to cover behavioral health services for adults, all states have opted to cover office-based counseling and therapy, as well as some combination of intensive community-based supports and services. States can provide these services through a variety of options. *See, e.g.*, 42 U.S.C. 1396d(13)(c); 42 U.S.C. 1396n(i). For an overview of state coverage of behavioral health services, see generally Jennifer Lav, *Policy Implications of Repealing the IMD Exclusion*, NAT'L HEALTH L. PROGRAM 4 (2018), <https://healthlaw.org/resource/policy-implications-of-repealing-the-imd-exclusion/>; Jennifer Lav & Kim Lewis, *Children's Mental Health Services: The Right to Community-Based Care*, NAT'L HEALTH L. PROGRAM 6 (2018), <https://healthlaw.org/resource/childrens-mental-health-services-the-right-to-community-based-care/>.

19. Musumeci et al., *supra* note 17, at 3. Forty-seven states have implemented at least one Section 1915(c) waiver to provide HCBS. 42 U.S.C. § 1396n(c). This Article will refer to 1915(c) (or Appendix K, which is the 1915(c) emergency authority) specifically when discussing HCBS covered under those waiver programs. States may also offer HCBS through their regular state plan service package. *See, e.g.*, 42 U.S.C. § 1396d(a)(13) (commonly used to cover rehabilitative services for behavioral health services); § 1396d(a)(8) (private duty nursing services); § 1396d(a)(24) (personal care services). State plan HCBS services are not subject to cost or enrollment caps. A few states cover HCBS through Section 1115 demonstration programs, which may encompass all or part of their Medicaid programs. Section 1115 of the Social Security Act limits these programs to novel, experimental projects. 42 U.S.C. § 1315(a); Musumeci et al., *supra* note 17.

20. *See* Molly O. Watts et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, KAISER FAM. FOUND. 3 (2020), <http://files.kff.org/attachment/Issue-Brief-Medicaid-Home-and-Community-Based-Services-Enrollment-and-Spending>.

21. 42 U.S.C. § 1396n(3). U.S. DEP'T. OF HEALTH & HUM. SERVS. OFF. OF THE ASS'T SEC'Y FOR PLAN. & EVAL., UNDERSTANDING MEDICAID HOME AND COMMUNITY SERVICES: A PRIMER 158 (2010). Peter Cunningham et al., *The Struggle to Provide Community-Based Care to Low-Income People with Serious Mental Illnesses*, 25 HEALTH AFFS. 694, 695 (2006) (discussing underfunded behavioral health programs).

22. PRESIDENT'S COMM. FOR PEOPLE WITH INTELL. DISABILITIES, REPORT TO THE PRESIDENT 2017: AMERICA'S DIRECT SUPPORT WORKFORCE CRISIS 8 (2017).

shortages.²³ Industry turnover rates are very high.²⁴ Medicaid, the primary payor for this work, pays very low rates generally, and often lower still for HCBS compared to institutional long-term care.²⁵

Poor wages and benefits in this industry stem from a history of discrimination and bias.²⁶ The 1935 Fair Labor Standards Act (FLSA), which established bedrock federal labor protections like overtime pay, sick leave, and hazard leave, did not extend these protections to domestic care workers, such as home health caregivers, most of whom were women of color.²⁷ The establishment of safety standards by the Occupational Safety and Health Administration in 1971 left them out again, even though the hands-on work leads to frequent injuries.²⁸ In 2013, the Department of Labor revised the federal Home Care Rule to tighten FLSA exemptions and thus extend labor protections, including overtime and minimum wage, to include up to 1.9 million home care workers.²⁹ While this rule did change how some states structure their HCBS programs, a recent Government Accountability Office (GAO) report found that the rule did not cause home care workers' earnings to increase relative to other occupations with similar education and training requirements.³⁰ In short, the low wages, limited benefits, and other conditions that affect the direct care workforce continues to inhibit HCBS capacity.

23. *Id.* at 14.

24. See Doris Parfaite-Claude, *NCI Survey on Direct Support Professional Turnover Now Available*, ANCOR (Feb. 11, 2020), <https://www.ancor.org/newsroom/news/nci-survey-direct-support-professional-turnover-now-available>.

25. PRESIDENT'S COMM. FOR PEOPLE WITH INTELL. DISABILITIES, *supra* note 22, at 25; Jennifer Ryan & Barbara C. Edwards, *Rebalancing Medicaid Long-Term Services and Supports*, HEALTH AFFS. 1 (2015), <https://www.healthaffairs.org/doi/10.1377/hpb20150917.439553/full/>.

26. Lisa I. Iezzoni et al., *Historical Mismatch Between Home-Based Care Policies and Laws Governing Home Care Workers*, 38 HEALTH AFFS. 973 (2019).

27. Eli Cahan, *Most Home Health Aides 'Can't Afford Not to Work' – Even When Lacking PPE*, KAISER HEALTH NEWS (Oct. 16, 2020), <https://khn.org/news/mostly-poor-minority-home-health-aides-lacking-ppe-share-plight-of-vulnerable-covid-patients/>.

28. *OSHA Celebrates 40 Years of Accomplishments in the Workplace*, U.S. OCCUPATIONAL SAFETY & HEALTH ADMIN. 16, <https://www.osha.gov/osha40/OSHA%20Timeline.pdf> (last visited Jan. 16, 2021); News Release, Bureau of Labor Statistics, *Employer-Reported Workplace Injuries and Illnesses – 2019* (Nov. 4, 2020), <https://www.bls.gov/news.release/pdf/osh.pdf> (showing that in 2019, the nursing assistants' injury incidence rate, 283.5 per 10,000 workers, exceeded that of construction laborers, tractor trailer drivers, and stock and material movers); Eileen Boris, *When the Home Is a Workplace*, DISSENT (Apr. 16, 2020), https://www.dissentmagazine.org/online_articles/when-the-home-is-a-workplace; Laura Walter, *Domestic Service Workers Vulnerable to Occupational Hazards*, EHS TODAY (Mar. 22, 2011), <https://www.ehstoday.com/standards/osha/article/21906424/domestic-service-workers-vulnerable-to-occupational-hazards>.

29. U.S. GOV'T ACCOUNTABILITY OFF., GAO-21-72, *FAIR LABOR STANDARDS ACT: OBSERVATIONS ON THE EFFECTS OF THE HOME CARE RULE 5* (2020). Because of legal challenges, the rule did not take effect until November 2015. *Id.* at 8–9.

30. *Id.* at 19–20.

Over the last fifty years, disability rights advocates, including self-advocates, have pushed to expand access to HCBS in fully integrated community settings. They have fought to promote self-determination and autonomy for all people with disabilities.³¹ Despite persistent barriers, they have achieved considerable success, including steadily increasing state and federal investments in HCBS provided in community settings relative to expenditures for care in institutions.³² This long, incremental, and ongoing push to adequately resource Medicaid HCBS has been foundational to enforce the right of people with disabilities to live in the community.³³ This right and community integration mandate was recognized by the Supreme Court in *Olmstead v. L.C. ex rel. Zimring*, which held that people with disabilities have the right to receive supports in the community that they would have otherwise received in an institution and that states have obligations to provide such services.³⁴ It has been twenty-two years since the Court decided *Olmstead*, yet many people who could be served in the community remain institutionalized or without necessary services.³⁵ This is harmful anytime, but the tragedies of the COVID-19 pandemic have put these delays and injustices in stark relief.

B. Federal Response to COVID-19 Lags for HCBS

COVID-19 has created a great demand for federal action to address health and safety concerns and services available for people who use HCBS, but the federal response did not adequately meet this demand in the first year of the COVID-19 pandemic. Whereas a whole national database already exists to collect data from nursing facilities, no similar system collects data for Medicaid HCBS participants in congregate settings or at home.³⁶ Likewise, in April 2020, the Centers for Medicare & Medicaid Services (CMS) announced a nursing facility transparency initiative that required facilities to report infections and outbreaks regularly to CDC and to inform residents of COVID-19 infections in

31. AMARILYS BERNACET ET AL., EXAMINING THE POTENTIAL FOR ADDITIONAL REBALANCING OF LONG-TERM SERVICES AND SUPPORTS 1 (2021).

32. *Id.*

33. *See id.*

34. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999). In recognizing this form of discrimination, the Court said it reflected “two evident judgments”: institutional placement of those who can be in the community perpetuates unwarranted assumptions about worthiness and capability to participate in community life, and institutional placement “severely diminishes the everyday life activities of individuals, including family relations, social contacts . . . and cultural enrichment.” *Id.* at 600–01.

35. *See* Samuel R. Bagenstos, *Taking Choice Seriously in Olmstead Jurisprudence*, 40 J. LEGAL MED. 5, 11–20 (2020) (discussing how demand for HCBS exceeds supply and the need for more robust, integrated community-based services).

36. Gloria L. Krahn, *A Call for Better Data on Prevalence and Health Surveillance of People with Intellectual and Developmental Disabilities*, 57 INTELL. & DEVELOPMENTAL DISABILITIES 357, 358, 365 (2019).

the facility when they occur.³⁷ In May 2020, it created an independent commission to address safety and quality in nursing facilities.³⁸ No similar national initiatives exist for HCBS.

The initial focus of the federal COVID-19 response on institutional settings also hurt the availability of HCBS providers. While some states increased funding for certain HCBS providers, these efforts have often failed to compensate for lost revenue due to decreased utilization and increased costs.³⁹ Congress included billions for provider relief with the CARES Act in April 2020, but the first recipients of this money went to Medicare providers, which left out many HCBS providers who depend on Medicaid funding.⁴⁰ An allocation of CARES Act funding dedicated to Medicaid-only providers, including many HCBS providers, was not released until June 2020, months after the first pandemic peak.⁴¹ The HEROES Act, passed by the House in May 2020, included a provision that would directly increase federal matching funds for Medicaid HCBS.⁴² Senate counter proposals at the time did not include any such provision, and it was not until March 2021 that the enhanced federal match for Medicaid HCBS finally passed.⁴³ This represents a lost opportunity that may have cost thousands of lives. The community-based services system needed more early and sustained support to meet people's needs during this extended emergency as "make-do" situations began to falter.

37. Press Release, Ctrs. for Medicare & Medicaid Servs., Trump Administration Announces New Nursing Homes COVID-19 Transparency Effort (Apr. 19, 2020), <https://www.cms.gov/newsroom/press-releases/trump-administration-announces-new-nursing-homes-covid-19-transparency-effort>.

38. Press Release, Ctrs. for Medicare & Medicaid Servs., CMS Announces Independent Commission to Address Safety and Quality in Nursing Homes (Apr. 30, 2020), <https://www.cms.gov/newsroom/press-releases/cms-announces-independent-commission-address-safety-and-quality-nursing-homes>. *But see Considerations for the Care and Treatment of Mental and Substance Use Disorders in the COVID-19 Epidemic: March 20, 2020*, SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN. (May 7, 2020), <https://www.samhsa.gov/sites/default/files/considerations-care-treatment-mental-substance-use-disorders-covid19.pdf> (recommending that "outpatient treatment options, when clinically appropriate, be used to the greatest extent possible").

39. MaryBeth Musumeci et al., *Options to Support Medicaid Providers in Response to COVID-19*, KAISER FAM. FOUND. (June 17, 2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/options-to-support-medicare-providers-in-response-to-covid-19/>.

40. *See generally CARES Act Provider Relief: General Information*, U.S. DEP'T OF HEALTH & HUM. SERVS., <https://www.hhs.gov/coronavirus/cares-act-provider-relief-fund/general-information/index.html> (last visited Jan. 6, 2020).

41. Press Release, U.S. Dep't of Health & Hum. Servs., HHS Announces Enhanced Provider Portal, Relief Fund Payments for Safety Net Hospitals, Medicaid & CHIP Providers (June 9, 2020), <https://www.hhs.gov/about/news/2020/06/09/hhs-announces-enhanced-provider-portal-relief-fund-payments-for-safety-net-hospitals-medicare-chip-providers.html>.

42. *H.R. 6800-The Heroes Act*, CONGRESS.GOV, <https://www.congress.gov/bill/116th-congress/house-bill/6800?q=%7B%22search%22%3A%5B%22hr+6800%22%5D%7D&r=1&s=1> (last visited Jan. 6, 2021); *The Heroes Act*, H.R. 6800, 116th Cong. § 30103 (2020).

43. *See The American Rescue Plan Act*, H.R. 1319, 9817, 117th Cong. (2021).

C. *The Effect of the COVID-19 Pandemic on Medicaid HCBS*

The COVID-19 pandemic has had a double-edged effect on access to HCBS. On one hand, the virus has disrupted services and forced many participants into isolation.⁴⁴ People with disabilities face elevated morbidity and mortality risks from COVID-19, not only because of the increased presence of conditions that may hamper immune response, but also because of the higher likelihood of living in congregate settings and the need for daily assistance.⁴⁵ Many people receiving HCBS require hands-on, face-to-face support, which increases exposure risk for both people with disabilities and their providers.⁴⁶ Various small-scale studies and widespread news reports suggest that people with disabilities in community settings and the workers who support them are at elevated risk.⁴⁷ For example, group home residents with intellectual disabilities in New York were over four times as likely to be diagnosed with COVID-19 and 7.78 times as likely to die from it compared to the general population.⁴⁸ COVID-19 has also had a profound impact on behavioral health across many populations. Young adults, Latinx and Black individuals, essential workers, unpaid caregivers for adults, and those already receiving treatment for psychiatric conditions all have experienced an increased incidence of adverse behavioral

44. Lynn Bonner, *Coronavirus Creates New Worries for People with Disabilities Who Depend on In-Home Care*, THE NEWS & OBSERVER (Apr. 24, 2020), <https://www.newsobserver.com/news/local/article242052866.html>.

45. See Powell, *supra* note 5, at 104–13; see also *People with Certain Medical Conditions*, CTRS. FOR DISEASE CONTROL & PREVENTION (Dec. 29, 2020), <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>; *People with Disabilities*, CTRS. FOR DISEASE CONTROL & PREVENTION (Sept. 11, 2020), [https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html#:~:text=Most%20people%20with%20disabilities%20are,of%20their%20underlying%20medical%20conditions](https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html#:~:text=Most%20people%20with%20disabilities%20are,of%20their%20underlying%20medical%20conditions;); Maya Sabatello et al., *People with Disabilities in COVID-19: Fixing Our Priorities*, 20 AM. J. BIOETHICS 187, 188 (2020) (discussing the marginalization of people with disabilities in health care and that they are more likely to have poorer health outcomes, including COVID-19 risk factors).

46. Musumeci et al., *supra* note 17, at 6.

47. Scott D. Landes et al., *COVID-19 Outcomes Among People with Intellectual and Developmental Disability Living in Residential Group Homes in New York State*, 13 DISABILITY & HEALTH J., Oct. 2020, at 2; Roni Caryn Rabin, *Developmental Disabilities Heighten Risk of COVID Death*, N.Y. TIMES (Nov. 11, 2020), <https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html>; Holbrook Mohr et al., *Thousands Sick from COVID-19 in Homes for the Disabled*, AP NEWS (June 11, 2020), <https://apnews.com/article/virus-outbreak-health-us-news-ap-top-news-weekend-reads-bdc1a68bcf73a79e0b6e96f7085ddd34>.

48. See Landes et al., *supra* note 47, at 3–4; see also James W. Lytle, *The Disparate Impact of COVID-19 on Individuals with Intellectual and Developmental Disabilities*, BILL OF HEALTH (Apr. 22, 2020), <https://blog.petrieflom.law.harvard.edu/2020/04/22/covid19-intellectual-developmental-disabilities-ppe/> (citing COVID-19 outbreaks at I/DD facilities and that people with I/DD receiving supports in NY were 5.34 times more likely than the general population to develop COVID-19 and 4.86 more likely to die from it).

health conditions throughout the pandemic.⁴⁹ Quarantine and other infection mitigation protocols have reduced access to community living, the availability of community-based providers, and visits from family and friends.⁵⁰ Many HCBS settings have shut down or temporarily altered their programs to reduce or eliminate face-to-face encounters.⁵¹

While COVID-19 has created additional problems in HCBS, it has also generated state policy responses that resulted in new services or HCBS delivery models that rely less on congregate services and reinforce the aims of *Olmstead* and the Americans with Disabilities Act (ADA).⁵² For example, some congregate adult day programs, which are often co-located with or near nursing facilities, were forced by the pandemic to explore alternative, socially-distanced services.⁵³ In many cases, this meant moving away from reliance on congregate settings and toward home-based, individualized care plans that align closely with the goals of promoting autonomy and community integration.⁵⁴ Of course, the pandemic has limited people's options for in-person social engagements, but people receiving services in their homes could choose activities they were comfortable with, such as going to a public park or socially-distanced visits with friends. In contrast, congregate day activities typically involved going to a senior center or similar setting, with less individual choice and interactions primarily with other people with similar disabilities or staff. Other temporary policy changes in response to the pandemic also address other facets of Medicaid's longstanding structural bias toward institutions. For example, increases to provider rates, policies that allow payments to family caregivers, and changes that broadened who can qualify to provide certain community-based services

49. Nirmita Panchel et al., *The Implications of COVID-19 for Mental Health and Substance Use*, KAISER FAM. FOUND. (Aug. 21, 2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/the-implications-of-covid-19-for-mental-health-and-substance-use/>; William Wan, *The Coronavirus Pandemic Is Pushing America into a Mental Health Crisis*, WASH. POST (May 4, 2020), <https://www.washingtonpost.com/health/2020/05/04/mental-health-coronavirus/>. See Mark E. Czeisler et al., *Mental Health, Substance Use, and Suicidal Ideation During the COVID-19 Pandemic — United States, June 24–30, 2020*, 69 MORBIDITY & MORTALITY WKLY. REP. 1049, 1052–53 (2020).

50. Bonner, *supra* note 44; Edwards, *supra* note 2.

51. *Impact of Covid-19 on Organizations Serving Individuals with Intellectual and Developmental Disabilities*, AVALERE HEALTH 2 (2020), https://www.ancor.org/sites/default/files/impact_of_covid-19_on_organizations_serving_individuals_with_idd.pdf; *Impact of Covid-19 on State Mental Health Services*, NRI 7 (2020), <http://nri-inc.org/media/1677/nri-2020-profiles-report-the-impact-of-covid-on-state-mental-health-systems.pdf> [hereinafter NRI Report].

52. Musumeci et al., *supra* note 10.

53. See, e.g., *Adult Day Services Provided During the COVID-19 Emergency FAQ*, MINN. DEP'T OF HUM. SERVS. (Dec. 12, 2020), <https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/aging/adult-day-covid-faq/adult-day-covid.jsp> [hereinafter *Adult Day Services Provided*].

54. See, e.g., *id.*

helped alleviate provider scarcity in some areas.⁵⁵ These changes should inspire new models for HCBS even after the public health emergency ends.

III. COVID-19 EMERGENCY CHANGES TO MEDICAID HCBS IMPROVED ACCESS TO CARE

Medicaid is a flexible and powerful tool to provide HCBS. As noted above, states have a range of options to provide community-based care and no state provides the same array of community-based services.⁵⁶ During the pandemic, states similarly made multiple changes to HCBS.⁵⁷ While the mechanism might vary, there are identifiable policy changes that would be beneficial to retain regardless of the emergency mechanism used or the state Medicaid program design.

During the COVID-19 pandemic, states have primarily relied on three important tools to temporarily modify their Medicaid programs.⁵⁸ First, Section 1135 permits the Secretary of Health and Human Services (HHS) to waive or modify certain Medicaid (and Medicare and CHIP) requirements.⁵⁹ Second, states have coupled Section 1135 waivers with state plan amendments to create something called “Medicaid Disaster Relief State Plan Amendments” to temporarily alter their Medicaid programs.⁶⁰ Third, states can use a 1915(c)

55. Musumeci et al., *supra* note 10.

56. States can cover an extremely broad array of services via 1915(c) waivers and Appendix K. 42 U.S.C. § 1396n(c)(4). *See generally* Musumeci et al., *supra* note 17.

57. Because states are quickly making numerous changes to modify their programs in response to the changing conditions of the pandemic, any list of state alternatives in the footnotes of this Article should be considered illustrative, not exhaustive.

58. *See* Leo Cuello, *Overview on Using Medicaid to Respond to COVID-19*, NAT’L HEALTH L. PROGRAM 1 (2020), <https://healthlaw.org/resource/overview-on-using-medicaid-to-respond-to-covid-19/>; *see also* *Inventory of Medicaid and CHIP Flexibilities and Authorities in the Event of a Disaster*, MEDICAID & CHIP COVERAGE LEARNING COLLABORATIVE 3–4 (Aug. 20, 2018), <https://www.medicaid.gov/state-resource-center/downloads/mac-learningcollaboratives/medicaid-chip-inventory.pdf>. All of the approved COVID-19-based changes to state Medicaid programs are available on the CMS website on the pages for the respective authorities. For the purposes of this Article, citations will be to the state and type of authority in the interest of clarity and brevity. *Coronavirus Disease 2019 (COVID-19)*, MEDICAID.GOV, <https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/coronavirus-disease-2019-covid-19/index.html> (last visited Nov. 9, 2020) (listing Medicaid & CHIP resources as well as links to approved changes under Section 1135, Appendix K, and state plan amendments; for SPAs and Section 1115 search for “COVID” to limit the approvals to the emergency approvals).

59. 42 U.S.C. § 1320b-5.

60. States use these disaster SPAs to amend their state plan in ways that are permitted outside of an emergency, but by also invoking the authority under 1135, states make these changes effective at an earlier date and waive other typical SPA requirements. *See* Héctor Hernández-Delgado, *Use of Emergency Medicaid State Plan Amendments During the COVID-19 Pandemic*, NAT’L HEALTH L. PROGRAM 1 (2020), <https://healthlaw.org/resource/use-of-emergency-medicaid-state-plan-amendments-during-the-covid-19-pandemic/>.

Appendix K amendment to temporarily modify existing 1915(c) waivers to meet participant’s needs during an emergency period.⁶¹ States have used these authorities to add services to support individuals with disabilities during the pandemic, to expand the provider pool, to stabilize the provider workforce, and to increase telehealth.⁶²

TABLE 1: MEDICAID FLEXIBILITIES TO RESPOND TO COVID-19

<i>Authority</i>	<i>What It Modifies</i>	<i>Preconditions</i>	<i>Expiration Date</i>
Section 1135 of the Social Security Act	Medicaid, Medicare, and CHIP	Presidential declaration of the emergency under the Stafford Act and declaration by the HHS Secretary of a public health emergency under Section 319 of the Public Health Service Act	End of the public health emergency

61. *Emergency Preparedness and Response for Home and Community Based Waivers (HCBS) 1915(c) Waivers*, CTRS. FOR MEDICARE & MEDICAID SERVS., <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> (last visited June 21, 2021). For example, states may use Appendix K amendments to a 1915(c) waiver to provide additional services, such as increased case management, to help an individual affected by a natural disaster, such as a hurricane, as they navigate changing circumstances in a geographic area of a state. *1915(c) Home and Community-Based Services Waiver Instructions and Technical Guidance: Appendix K: Emergency Preparedness and Response*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.medicaid.gov/state-resource-center/downloads/1915c-appendix-k-instructions.pdf> (last visited June 21, 2021) [hereinafter *Appendix K Instructions*].

62. States also made other changes that impacted people with disabilities and their ability to be in the community that are not addressed in this Article. For example, several states suspended premiums and other requirements for Medicaid coverage for workers with disabilities programs so that those individuals would not face loss of Medicaid coverage due to job or income changes. *See, e.g.*, N.C. DEP’T OF HEALTH & HUM. SERVS., NC-20-0008, NORTH CAROLINA STATE PLAN AMENDMENT (SPA) 20-0008 (2020); ALASKA DEP’T OF HEALTH & SOC. SERVS., AK-20-0003, ALASKA STATE PLAN AMENDMENT (SPA) TRANSMITTAL NUMBER 20-0003 (2020); WYO. OFF. OF HEALTH CARE FIN., WY-20-0003, WYOMING STATE PLAN AMENDMENT (SPA) 20-0003 (2020). A handful of states have also used section 1115 demonstration waivers to make changes to the way the state delivers HCBS, although this vehicle is particularly ill-suited to respond to a public health crisis. *See* Jane Perkins and Catherine McKee, *Making Sure Medicaid Is Ready for Public Health Emergencies*, NAT’L HEALTH L. PROGRAM (July 15, 2021), <https://healthlaw.org/resource/making-sure-medicaid-is-ready-for-public-health-emergencies/>.

<i>Authority</i>	<i>What It Modifies</i>	<i>Preconditions</i>	<i>Expiration Date</i>
Medicaid Disaster Relief State Plan Amendments	Medicaid State Plans	Same as Section 1135	End of the public health emergency or any earlier approved date elected by a state
Appendix K	Section 1915(c) home- and community-based waivers	Only available during an “emergency,” but no specific statutory prerequisites	Typically one year from the earliest effective date (or an earlier date chosen by the state), but under the COVID-19 pandemic this was extended to no later than six months after the end of the public health emergency ⁶³

A. *Ensuring Sufficient Providers*

As noted above, inadequate access to HCBS providers predates COVID-19, but the pandemic created new threats to an already stressed HCBS system with its fragile network of supports and providers.⁶⁴ The shortcomings of federal and state COVID-19 responses worsened the situation for both HCBS participants and the direct support professionals (DSPs) providing HCBS services.⁶⁵

Many direct care workers stayed on the job even during lockdowns, thus increasing their risk of contracting COVID-19.⁶⁶ Many worked even longer hours with more clients due to staff shortages from sickness or quarantine.⁶⁷ The

63. Letter from Anne Marie Costello, Acting Deputy Adm’r & Dir., Ctrs. for Medicare & Medicaid Servs., to State Health Offs. 3, 7 (Dec. 22, 2020).

64. According to a survey of State Mental Health Agencies (SMHAs), in most states, in-person services have been replaced by telehealth, but in at least six states (fifteen percent of respondents), telehealth has not increased to fill the gap. Additionally, seventy-three percent of states reported that community-based providers have had to reduce staff and twenty percent have had providers close. NRI Report, *supra* note 39, at 1.

65. Musumeci et al., *supra* note 10.

66. Ulf Karlsson & Carl-Johan Fraenkel, Editorial, *COVID-19: Risks to Healthcare Workers and Their Families*, BMJ (Oct. 28, 2020), <https://www.bmj.com/content/bmj/371/bmj.m3944.full.pdf>.

67. Shaun Heasley, *COVID-19 Taking a Toll on Direct Support Professionals*, DISABILITY SCOOP (Aug. 14, 2020), <https://www.disabilityscoop.com/2020/08/14/covid-19-taking-a-toll-on-direct-support-professionals/28729/>.

hands-on work makes it more difficult to socially distance, and many direct care workers lacked adequate access to PPE.⁶⁸ Many direct care workers became sick or had to quarantine.⁶⁹ That elevated risk of direct care work may also reinforce the starkly disproportionate impact of COVID-19, especially on Black and Latinx communities. Black and other people of color make up over half of the direct care workforce.⁷⁰ Over a quarter are Black women.⁷¹ No comprehensive occupational data exists for home health aides, so the true impact of the disease on these workers remains largely unquantified. Limited data has suggested that mortality among direct care workers has been higher for males, older adults, non-Hispanic Asians, and non-Hispanic Blacks.⁷² In general, Black health care workers and their families are particularly likely to know someone who has died from the virus and to experience a negative impact on their ability to pay for basic needs.⁷³ Taken together, these factors contribute to increased stress on the direct care network, with workers more likely to be absent due to quarantine or illness.⁷⁴

Adding to the difficult situation, just over one in four direct care workers are parents, most of whom are single mothers.⁷⁵ When their children lost access to

68. See Cahan, *supra* note 27; see also Michael Martz, 'Us Against Them': Workers Cite Racial Divide on Front Line of Long-Term-Care Fight Against COVID-19, RICH. TIMES-DISPATCH (Aug. 14, 2020), https://richmond.com/news/virginia/us-against-them-workers-cite-racial-divide-on-front-line-of-long-term-care-fight/article_225839e0-82f1-5668-9da0-a92ced009e1a.html.

69. Cahan, *supra* note 27; Thomas Goldsmith, *Short Staffing an Issue at NC Nursing Homes Marked by COVID-19 Outbreaks*, N.C. HEALTH NEWS (Apr. 20, 2020), <https://www.northcarolinahealthnews.org/2020/04/20/short-staffing-an-issue-at-nc-nursing-homes-marked-by-covid-19-outbreaks/>.

70. See Stephen Campbell, *Racial and Gender Disparities Within the Direct Care Workforce: Five Key Findings*, PHI 6 (2017), <https://phinational.org/wp-content/uploads/2017/11/Racial-and-Gender-Disparities-in-DCW-PHI-2017.pdf>.

71. *Id.*

72. Michelle Hughes et al., *Update: Characteristics of Health Care Personnel with COVID-19 – United States (Feb. 12–July 16, 2020)*, 69 MORBIDITY & MORTALITY WKLY. REP. 1364, 1366 tbl. 2 (2020) (noting very few states include occupation-type data and fewer include job setting categorization). See also Cahan, *supra* note 27; *Lost on the Frontline*, THE GUARDIAN & KAISER HEALTH NEWS, <https://www.theguardian.com/us-news/ng-interactive/2020/aug/11/lost-on-the-frontline-covid-19-coronavirus-us-healthcare-workers-deaths-database> (last visited Nov. 8, 2020) (documenting at least 1361 U.S. health care worker deaths since COVID-19 began).

73. Samantha Artiga et al., *COVID-19 Risks and Impacts Among Health Care Workers by Race/Ethnicity*, KAISER FAM. FOUND. (Nov. 11, 2020), <https://www.kff.org/report-section/covid-19-risks-and-impacts-among-health-care-workers-by-race-ethnicity-issue-brief/>.

74. See David Machledt, *Disability, Race, and Structural Inequity: COVID-19 and the Long-Term Care Workforce*, NAT'L HEALTH L. PROGRAM (Apr. 29, 2020), <https://healthlaw.org/disability-race-and-structural-inequity-covid-19-and-the-long-term-care-workforce/>; Theresa A. Allison et al., *Extreme Vulnerability of Home Care Workers During the COVID-19 Pandemic—A Call to Action*, 180 JAMA INTERNAL MED. 1459, 1460 (2020).

75. *Workforce Data Center*, PHI, <https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Parental+Status> (last visited Nov. 14, 2020) (noting twenty-

daycare or were placed in virtual learning situations at home due to COVID-19, many of these parents have had to cut back on providing HCBS.⁷⁶ Even in two-parent households, the child-care responsibilities still fall mostly on women's shoulders.⁷⁷ Nearly nine in ten direct care workers are women.⁷⁸ As of May 2021, 2.3 million fewer women were active in the workforce than prior to the pandemic. Many face added barriers to return, such as child care.⁷⁹ On top of these other factors that have constricted the supply of home care workers, COVID-19 increased demand for better-paying facility-based work, which has further depleted the availability of home care workers.⁸⁰

These stresses to the HCBS workforce have amplified the need to boost resources toward community-based services. One of the few bright spots in the response to COVID-19 has been state efforts to improve direct care worker retention and preserve access to services through policy changes, including higher rates and more flexibility for HCBS providers.⁸¹ The changes also provided HCBS participants more options to reduce the number of direct care workers they use and thereby limit their potential COVID-19 exposure.⁸² Some state policies, such as allowing family caregivers to be paid to provide services rather than hiring an agency or other direct care staff, have been available in a

seven percent of DSPs are parents with dependent children); COMM. ON FUTURE HEALTH CARE WORKFORCE FOR OLDER AMs., INST. MED., RETOOLING FOR AN AGING AMERICA: BUILDING THE HEALTH CARE WORKFORCE 204-05 (2008) (finding forty-three percent of female direct care workers were parents, while twenty-four percent were single mothers).

76. Goldsmith, *supra* note 69.

77. PEW RSCH. CTR., RAISING KIDS AND RUNNING A HOUSEHOLD: HOW WORKING PARENTS SHARE THE LOAD 3 (2015).

78. PHI, U.S. HOME CARE WORKERS: KEY FACTS 3 (2018).

79. Megan Cassella, POLITICO, "The pandemic drove women out of the workforce. Will they come back?" (July 22, 2021), <https://www.politico.com/news/2021/07/22/coronavirus-pandemic-women-workforce-500329>.

80. For more on the provider shortage issue under COVID-19, see Machledt, *supra* note 74. See also Jennifer Lav et al., *Keep Essential Care: Direct Service Professionals*, NAT'L HEALTH L. PROGRAM (Apr. 13, 2020), <https://healthlaw.org/keep-essential-care-direct-service-professionals/>; Goldsmith, *supra* note 69 (citing the existing staffing shortage and impact of COVID-19 and discussing the relationship between short staffing and COVID-19 outbreaks); Emma Cott et al., *Low Pay, High Risk: Nursing Home Workers Confront Coronavirus Dilemma*, N.Y. TIMES, Mar. 31, 2020, <https://www.nytimes.com/video/us/100000007046988/nursing-home-coronavirus.html?action=click&module=video-series-bar®ion=header&pgtype=Article&playlistId=video/coronavirus-news-update> (nursing assistants employed at nursing facilities discussing risks, dual employment as home health aides, their own risks, and risk of spreading to others including between patients); Allison et al., *supra* note 72 (citing the COVID-19 infections in nursing facility staff and lack of information about home care staff and home health worker disparities as the result of structural racism).

81. See generally Edwards, *supra* note 9.

82. *Id.*

number of states for years.⁸³ Other changes, such as modifying provider qualifications or providing short-term retention payments, have deviated from typical state HCBS policies and practices.⁸⁴ Two widely-adopted changes—paying for HCBS staff in acute care situations and providing expanded retention payments—both promote retention of workers and otherwise help support people with disabilities.⁸⁵

1. Expanding the Provider Pool

State Medicaid agencies have expanded the provider pool by allowing qualified providers to work across state lines, broadening the scope of services HCBS providers can provide, temporarily relaxing provider qualifications, and paying family caregivers for services provided.⁸⁶ All states used Section 1135 waivers to allow providers qualified in one state to provide the same or similar services in another.⁸⁷ This practical change is especially helpful in communities near state borders, and presents few risks as qualifications are typically similar from one state to another.⁸⁸ Similarly, many states used Appendix K to allow different types of HCBS providers to provide more services.⁸⁹ A handful of states also used state plan amendments to expand behavioral health providers through relatively small changes to provider qualifications, with little associated risks to service quality.⁹⁰

83. See LYNN FRISS FEINBERG ET AL., FAM. CAREGIVER ALL., THE STATE OF THE STATES IN FAMILY CAREGIVER SUPPORT: A 50-STATE STUDY 12 (2004).

84. See Edwards, *supra* note 9.

85. *Id.*

86. See Edwards, *supra* note 9 at 5–7; see also *States Use Appendix K and Emergency Waivers to Support Home- and Community-Based Services in Response to COVID-19*, NAT'L ACAD. FOR STATE HEALTH POL'Y, <https://www.nashp.org/states-use-appendix-k-waivers-to-support-home-and-community-based-services-in-response-to-covid-19/> (last visited Oct. 13, 2020) [hereinafter NASHP Appendix K Map]; *Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19*, KAISER FAM. FOUND., <https://www.kff.org/medicaid/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/> (last visited Nov. 2, 2020) [hereinafter KFF COVID-19 Tracker].

87. KFF COVID-19 Tracker, *supra* note 86.

88. See, e.g., Angelinna Walker, *2019 State-by-State Guide to RN Licensure: eNLC Update*, NURSE.ORG (Mar. 14, 2018), <https://nurse.org/articles/guide-to-registered-nurse-licensure-by-state/> (describing the basic commonalities in nurse licensure). All states used 1135 while forty-nine states used Appendix K to modify provider qualifications, but not all states modified provider qualifications for all waivers in that state. See generally NASHP Appendix K Map, *supra* note 86.

89. Edwards, *supra* note 9; NASHP Appendix K Map, *supra* note 86.

90. See, e.g., OKLA. HEALTH CARE AUTH., OK-20-0032, OKLAHOMA STATE PLAN AMENDMENT (SPA) 20-0032 (2020) (allowing independently licensed psychologists to provide crisis intervention services); ALASKA DEP'T OF HEALTH & SOC. SERVS., AK-20-0003, ALASKA STATE PLAN AMENDMENT (SPA) TRANSMITTAL NUMBER 20-0003 (2020) (permitting master's degree-level students who have completed coursework but not completed required internships or practicum to practice as unlicensed mental health professionals).

States also used emergency-based changes to shorten the time between hiring an individual and allowing them to provide services or to otherwise reduce hiring requirements.⁹¹ For example, many states used Appendix K to allow a worker to start before required background checks were completed or to allow training to occur after starting work.⁹² Similarly, a minority of states made more sweeping changes to behavioral health provider qualifications, including suspending training requirements, relaxing staffing ratios, and waiving requirements to maintain fidelity to evidence-based treatment models.⁹³ While these changes to HCBS providers may be helpful to maintain staffing levels during the emergency, many of the provider qualifications that were waived are important for health and safety. For example, although suspending training requirements before a direct care worker begins working with an individual may help shorten the time between hiring and providing direct services, that worker may miss out on important training about a person's health needs, such as actions or movements a person who is non-speaking uses to communicate distress or nutritional needs to help manage medical conditions.

Some states have allowed family to be paid caregivers as a strategy to mitigate the problem of provider shortages and to allow HCBS participants to limit contact with people from outside their home during the pandemic.⁹⁴ Because most HCBS participants receive services in their homes, they often have had to choose between getting the services they need or risking exposure to an outside worker, who may or may not be providing HCBS to other households as well.⁹⁵ One solution is to pay household members or family members who are already in the individual's "bubble" to do that work. Medicaid typically restricts legally responsible relatives from becoming paid providers,

91. Edwards, *supra* note 9, at 7.

92. *Id.* at 8. See, e.g., N.M. DEP'T OF HEALTH, NM.0173.R06.02, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (delaying requirements for training and background checks and suspending certain supervision requirements).

93. See, e.g., N.C. DEP'T OF HEALTH & HUM. SERVS., NC-20-0008, NORTH CAROLINA STATE PLAN AMENDMENT (SPA) 20-0008 (2020) (suspending Assertive Community Treatment (ACT) requirements for team composition if staff are sick or unavailable, suspending the staff to beneficiary ratio, and suspending fidelity to the model; also suspending training and supervision requirements for mobile crisis management services, training requirements for intensive home-based services, and community support team requirements for team composition if staff are sick or unavailable); N.J. DEP'T OF HUM. SERVS., NJ-20-0003, NEW JERSEY STATE PLAN AMENDMENT (SPA) 20-0003 (2020) (suspending staffing ratio requirement for children's intensive behavioral health services).

94. Elizabeth Edwards, *Q & A: Relatives as Paid Providers*, NAT'L HEALTH L. PROGRAM 1, 4 (2014), <https://healthlaw.org/resource/qa-relatives-as-paid-providers/>.

95. MaryBeth Musumeci, *How Are States Supporting Medicaid Home and Community-Based Services During the COVID-19 Crisis?*, KAISER FAM. FOUND. (May 5, 2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/how-are-states-supporting-medicaid-home-and-community-based-services-during-the-covid-19-crisis/>.

but has such options via HCBS waivers.⁹⁶ Though states could already allow paid family caregivers for most HCBS under 1915(c) before the pandemic, not all elected to do so.⁹⁷ To respond to the COVID-19 crisis, about half of the states used Appendix K to add or expand the ability to pay family caregivers for at least one 1915(c) waiver program.⁹⁸ Other states used Section 1135 authority to allow the same for state plan HCBS.⁹⁹ Depending on a state's rules, particularly its nursing scope of practice and delegation rules, family members can sometimes also provide services with higher levels of care that non-licensed direct care workers may not be allowed to provide.¹⁰⁰ Unpaid family caregiver supports have long been a critical component that help many people, including those receiving Medicaid HCBS, stay in their home rather than in an institution.¹⁰¹ For most Medicaid HCBS, substituting such supports in lieu of paid supports should only happen if the family caregiver does so willingly.¹⁰² However, for many, unpaid supports feel compelled due to decreasing paid supports.¹⁰³ Ultimately, a person's network of caregivers is a balance of paid supports as needed, with uncompensated family caregiver support only where such care has been volunteered and is done so at levels that allow supports to have appropriate breaks from caregiving.¹⁰⁴ Although paying family caregivers can improve access to care, in an HCBS system that often exploits unpaid family

96. Edwards, *supra* note 94, at 1–2.

97. *Id.* at 3; Musumeci et al., *supra* note 17, at 7, 15 (showing only a few states allow relative providers for state plan personal care and thirty states allow certain legally responsible relatives to be paid providers under waiver services).

98. Thirty-nine states used Appendix K to temporarily permit payment for services rendered by family members or legally responsible relatives. Appendix K for AK, AL, AZ, CA, CO, CT, DC, DE, FL, GA, HI, ID, IL, IN, KS, LA, MD, ME, MN, MO, MS, MT, NC, ND, NH, NJ, NM, NV, OH, OK, PA, RI, SC, SD, UT, VA, VT, WI, & WV, *supra* note 58. *See also* KFF COVID-19 Tracker, *supra* note 86.

99. Thirteen states used Section 1135 to allow legally responsible individuals to provide personal care services, and for some states 1915(k) services. Section 1135 for AK, GA, IA, LA, MD, MT, NH, NJ, NM, NY, ND, PA, & VT, *id.*

100. Edwards, *supra* note 94, at 3; Letter from Timothy M. Westmoreland, Dir., Health Care Fin. Admin., to State Medicaid Dir. 14 (July 25, 2000), https://www.nasddd.org/uploads/documents/Olmstead_letter_31.pdf. *See also* Musumeci et al., *supra* note 17, at 53 n. 68.

101. Neva Kaye & Salom Teshale, *Medicaid Supports for Family Caregivers*, NAT'L ACAD. FOR STATE HEALTH POL'Y (Oct. 29, 2020), <https://www.nashp.org/medicaid-supports-for-family-caregivers/#toggle-id-3>.

102. 42 C.F.R. § 441.301(c)(2)(v) (2020).

103. L. ANDERSON ET AL., MINN.: RSCH & TRAINING CTR. ON CMTY. INTEGRATION, FAMILY AND INDIVIDUAL NEEDS FOR DISABILITY SUPPORTS (V.2) COMMUNITY REPORT 2017, at 23 (2017).

104. Kaye & Teshale, *supra* note 101. *See also* Susan C. Reinhard et al., *Valuing the Invaluable: 2019 Update*, AARP PUB. POL'Y INST. 5, 18 (Nov. 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>.

labor to fill gaps in services, paying family caregivers may lead to increased stress on those informal networks of support.¹⁰⁵

2. Increasing Payment Rates

Another basic strategy to improve workforce retention is to increase wages, particularly when workers are faced with hazardous situations. Most of the early support for community-based providers came from states via the emergency Medicaid authorities.¹⁰⁶ This is especially true for providers of community-based services through 1915(c) waivers.¹⁰⁷ Over half of the states used Appendix K amendments to allow temporary increases to HCBS provider rates.¹⁰⁸ Increases varied by waiver, service, and conditions under which a higher rate would be paid.¹⁰⁹ Some Appendix K amendments were approved to increase rates across the range of waiver services up to a certain amount, which was usually a percentage of the current rate, while others tiered the increases.¹¹⁰ States also included rate increases up to a certain amount in areas determined by the state to have provider shortages or tied the increased rate to the COVID-19 status of the HCBS participant.¹¹¹ In comparison to the large number of states that have used Appendix K to address rates, only a minority of states have

105. Edwards, *supra* note 94, at 4. See Reinhard et al., *supra* note 104.

106. See KFF COVID-19 Tracker, *supra* note 86.

107. See *id.*

108. See *id.*

109. Compare CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID.GOV, AR.0188.R05.04, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (issuing tiered payments based on beneficiary acuity), with CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID.GOV, LA. 0121.R07.02, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (using an enhanced provider reimbursement rate based on current market factors and added costs), and CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICAID.GOV, MI 0167.06.01, MI 4119.06.01, MI 0438.03.01, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (applying rate increases to certain services).

110. Compare, e.g., ARK. DEP'T OF HUM. SERVS., AR.0188.R05.04, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020), with ARK. DEP'T OF HUM. SERVS., AR.0195.R05.02, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (providing tiered rates), and ALASKA DEP'T OF HEALTH & SOC. SERVS., AK.0260.R05.09, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE (2020) (providing a mix of rate adjustments), and TENN. DIV. OF TENNCARE, TN.0128.R06.01, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (providing percentage increases).

111. See, e.g., TENN. DIV. OF TENNCARE, TN.0128.R06.01, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (providing a general rate increase of ten percent or thirty percent depending on the service, but also a per diem add-on payment to existing rate for specific services when those services are provided to a confirmed COVID-19-positive individual).

requested state plan amendments and even fewer have done so for behavioral health services.¹¹²

Several states explicitly mentioned PPE, cleaning supplies, and other COVID-related needs as part of the reason for the rate increase, although sometimes only for specific providers.¹¹³ Some states also addressed the need for PPE by increasing the amount of services provided or changing service definitions related to medical supplies to include PPE.¹¹⁴ States also increased rates to specifically address overtime pay in instances where overtime was

112. *See, e.g.*, CAL. DEP'T OF HEALTH CARE SERVS., CA-20-0024, CALIFORNIA STATE PLAN AMENDMENT (SPA) 20-0024 (2020) (increasing interim payments and waiving limitations of "usual and customary charge" or "statewide maximum allowance" for non-narcotic treatment programs and specialty mental health services); MASS. OFF. OF MEDICAID, MASS. EXEC. OFF. OF HEALTH & HUM. SERVS., MA-20-0008, MASSACHUSETTS STATE PLAN AMENDMENT (SPA) 20-0008 (2020) (increasing rates for Applied Behavioral Analysis). States that provide behavioral health services via managed care could use directed payments to temporarily increase rates for specific services, but states are generally not pursuing this option for community-based behavioral health services. *See* CTRS. FOR MEDICARE & MEDICAID SERVS., DEP'T OF HEALTH & HUM. SERVS., CMS INFORMATIONAL BULLETIN: MEDICAID MANAGED CARE OPTIONS IN RESPONDING TO COVID-19, at 6 (2020); *see also* Musumeci et al., *supra* note 39. State plan amendments for other services include: WASH. STATE HEALTH CARE AUTH., WA-20-0021, WASHINGTON STATE PLAN AMENDMENT (SPA) 20-0021 (2020) (private duty nursing); ARK DEP'T OF HUM. SERVS., AR-20-0014, ARKANSAS STATE PLAN AMENDMENT (SPA) 20-0014 (2020) (NF, home health, personal care, hospice, assisted living facilities, residential care facilities, psychiatric residential treatment facilities, and day habilitation); CAL. DEP'T OF HEALTH CARE SERVS., CA-20-0024, CALIFORNIA STATE PLAN AMENDMENT (SPA) 20-0024 (2020) (IHSS).

113. *See, e.g.*, ALA. MEDICAID AGENCY, ID 0001.R08.04, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020); HAW. DEP'T OF HUM. SERVS., HI.0013.R07.08, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020); ILL. DEP'T OF HEALTHCARE & FAM. SERVS., IL.0143.R06.06, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020); N.Y. STATE DEP'T OF HEALTH, NY 0238.R06.01, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE (2020) (respite and community habilitation providers).

114. *See, e.g.*, ALA. MEDICAID AGENCY, ID 0001.R08.04, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020); COLO. DEP'T OF HEALTH CARE POL'Y & FIN., CO.0006.R08.05, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE (2020) (allowing the specialized medical equipment and supplies service to purchase PPE; amendments for DE, HI, MS, PA, and WA allow the same); MICH. MED. SERVS. ADMIN., MI.0233.R05.02, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (MI Choice expanded goods and services to include purchase of PPE, disinfection supplies, and purchase of delivery service membership or monthly fees such as grocery delivery membership, and MI Health Link added PPE to adaptive medical equipment and supplies); MISS. DIV. OF MEDICAID, MS.0255.R05.02, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (adding PPE as a service); N.C. DEP'T OF HEALTH & HUM. SERVS., NC.0132.R07.03, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE (2020) (allowing on-demand quick procurement of PPE through case management and purchase of sanitation and other COVID-19 related supplies through individual goods and services); MD. DEP'T OF HEALTH, MD.1466.R01.02, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE (2020) (allowing self-directed budget modification and individual and family directed goods and services).

required because of staff shortages.¹¹⁵ While some states specified the use of the increased rate, other states implemented general increases.¹¹⁶ States that provided more broad access to PPE, including access to PPE through a variety of providers and mechanisms, responded more directly to the need posed by COVID-19. But for many people, the need for PPE is not solely COVID-19-related and states should look at keeping improved access to PPE and examine whether the broader array of purchasing options could be expanded to other goods and services, as those purchasing options may have been less costly and may also have been faster.

3. Retainer Payments

Retainer payments are critical to maintaining providers for HCBS.¹¹⁷ These payments to waiver-based HCBS providers when participants are temporarily hospitalized or otherwise unavailable to receive services allow the participant to ensure the same providers will be available to support them upon their return.¹¹⁸ Typically, without such retainer payments, if an individual is not using their HCBS, direct care workers do not receive any payment and may have to look for other work or ask to be reassigned to new clients.¹¹⁹ Given the dearth of direct care workers, it may be difficult to find another person to fill that role when the participant is discharged, which may lead to an individual missing necessary services during an important transition back to home.¹²⁰ A lack of services could lead to a greater burden on unpaid natural supports, such as family caregivers, and for many it could sharply increase their risk of institutionalization.¹²¹

115. See, e.g., ALA. MEDICAID AGENCY, ID 0001.R08.04, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020); ARK. DEP'T OF HUM. SERVS., 20-0014, ARKANSAS STATE PLAN AMENDMENT (SPA) 20-0014 (2020).

116. Compare MINN. DEP'T OF HUM. SERVS., 0025.R08.12, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (requiring at least eighty percent of increased rate to be used to increase wages, salaries, and benefits for direct care workers, as well as any corresponding taxes, with the remaining additional revenue to be used for activities and items needed to support compliance with CDC guidance on sanitation and PPE), with TENN. DIV. OF TENNCARE, TN.0128.R06.01, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020) (containing no such requirements for how the increased rate is to be used).

117. See Letter from Timothy M. Westmoreland, *supra* note 100, at 8; DISABLED & ELDERLY HEALTH PROGRAMS GRP., CTRS. FOR MEDICARE & MEDICAID SERVS., APPLICATION FOR A §1915(C) HOME AND COMMUNITY-BASED WAIVER: INSTRUCTIONS, TECHNICAL GUIDE AND REVIEW CRITERIA 74 (2019).

118. NAT'L MLTSS HEALTH PLAN ASS'N, MANAGED CARE PROVIDER PAYMENT PATHWAYS DURING COVID-19: ADVANCED PAYMENTS AND RETAINER PAYMENTS 2 (2020).

119. See Mike Ervin, *The Direct Care Worker Crisis*, PROGRESSIVE (Mar. 26, 2020), <https://progressive.org/magazine/the-direct-care-worker-crisis-ervin/>.

120. Machledt, *supra* note 74.

121. Ervin, *supra* note 119.

Although long identified as an important practice to keep people in the community, prior to COVID-19, retainer payments were uncommon in HCBS waivers.¹²² During the pandemic, however, most states have authorized retainer payments in some form or fashion for 1915(c) waiver services.¹²³ Like other changes, the specifics vary by service and payments are time limited.¹²⁴ Individuals have used retainer payments in situations where the individual was forced to limit interpersonal contacts to protect their own health and thus had to limit paid services while they temporarily relocated to stay with family or others, or while they are hospitalized.¹²⁵

4. Permitting HCBS Providers in Acute Care Settings

A majority of states have used Appendix K to authorize waiver-based HCBS staff to provide support in acute care settings, thereby permitting direct care workers or other companions to accompany a person with a disability when they enter a hospital.¹²⁶ Having a familiar staff in a hospital setting can reduce stress and help ensure the individual's needs are met.¹²⁷ This has been particularly relevant for individuals with needs not easily met by hospital staff, such as specialized communication and behavioral needs.¹²⁸ This significant access gap existed before COVID-19, but became even more apparent during the pandemic.

Although a majority of states are allowing HCBS providers in acute settings during the pandemic through Appendix K, many of these states limited the

122. See KFF COVID-19 Tracker, *supra* note 86 (showing thirty-nine states added temporary retainer payments through section 1915(c) waivers in response to COVID-19, indicating that these payments were not in use previously).

123. *Id.* (listing thirty-nine states using Appendix K Amendments, five states using Section 1115, and three states using Section 1135 (with overlap of states between authorities), including retainer payments to address emergency-related issues). See also MaryBeth Musumeci et al., *supra* note 39. Retainer payments typically reflect the limited time allowed by Medicaid for a nursing facility bed hold, which refers to the practice of paying the facility to keep the person's spot at the facility while they are elsewhere. During COVID-19, state authority to allow HCBS retainer payments have been allowed to be consecutively renewed several times. CTRS. FOR MEDICARE & MEDICAID SERVS., COVID-19 FREQUENTLY ASKED QUESTIONS (FAQS) FOR STATE MEDICAID AND CHILDREN'S HEALTH INSURANCE PROGRAM (CHIP) AGENCIES 99, 102 (2021).

124. See, e.g., ILL. DEP'T OF HEALTHCARE & FAM. SERVS., IL.0143.R06.06, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020).

125. See ALA. MEDICAID AGENCY, ID 0001.R08.04, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE AND COVID-19 ADDENDUM (2020).

126. KFF COVID-19 Tracker, *supra* note 86. At least one state, Oregon, has also amended its state plan temporarily to allow for behavioral health HCBS services in acute care settings. OR. HEALTH AUTH., OR-20-0011, OREGON STATE PLAN AMENDMENT (SPA) 20-0011 (2020).

127. NCD Statement Regarding Direct Support Professionals and COVID-19 Hospital Visit Rules, NAT'L COUNCIL ON DISABILITY (May 27, 2020), <https://ncd.gov/newsroom/2020/ncd-statement-dsp-covid-19-hospital-visit-rules> [hereinafter *NCD Statement*].

128. See OR. HEALTH AUTH., OR-20-0011, OREGON STATE PLAN AMENDMENT (SPA) 20-0011 (2020).

flexibility to certain services or set strict parameters about when it was allowed.¹²⁹ The CARES Act amended 42 U.S.C. § 1396(h) to allow, but not require, states to pay for some kinds of HCBS in acute care settings as long as those services meet certain conditions.¹³⁰ Thus, this change permits states to provide for services in acute settings outside the limited realm of Appendix K amendments during emergencies.¹³¹

B. Expanding Access to Services

1. Changes and Additions to Services

In response to COVID-19, state Medicaid agencies moved to add some HCBS and/or relax limits on existing HCBS to support people under the drastically changing pandemic circumstances.¹³² This included increasing or adding meal delivery services for 1915(c) waiver participants so people could maintain quarantine and isolation, and switching services from delivery in congregate to in-homes settings.¹³³ For example, many states replaced adult day services, which usually include monitoring, health checks, activities, and at least one meal, with a combination of in-home supports and increased meal

129. *NCD Statement, supra* note 126; *see, e.g., OCR Resolves Complaints After State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19*, U.S. DEP'T OF HEALTH & HUM. SERVS. (June 9, 2020), <https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html>.

130. Coronavirus Aid, Relief, and Economic Security (CARES) Act, Pub. L. No. 116-136, § 3715, 134 Stat. 281, 424–25 (2020) (amending 42 U.S.C. § 1396a(h) to allow Section 1915(c) services in acute settings). *See also* ELAYNE J. HEISLER, CONG. RSCH SERV., R46334, SELECTED HEALTH PROVISIONS IN TITLE III OF THE CARES ACT (P.L. 116-136) 1, 50–51 (2020). It is not clear that CMS has operationalized this change yet in the Section 1915(c) waiver application, which is also the amendment mechanism. CTRS. FOR MEDICARE & MEDICAID SERVS., APPLICATION FOR A §1915(C) HCBS WAIVER, HCBS WAIVER APPLICATION VERSION 3.6, at 1, 10 (2021) (reflecting the current waiver application required assurance from states that waiver services are not furnished in institutional facilities thus not showing the CARES Act option for HCBS in acute care settings).

131. *See* HEISLER, *supra* note 130 (discussing the CARES Act amendment that expands the ability of states to permit payment for HCBS care in acute settings through multiple HCBS authorities); *see also Appendix K Instructions, supra* note 61, at 11 (describing pre-CARES Act authority under 1915(c) Appendix K amendments to allow HCBS in acute care settings during emergencies).

132. Edwards, *supra* note 9, at 12 (detailing certain states' approved Appendix Ks that provide flexibility in HCBS rates, offer remote services, lift respite limits, and extend certifications during the pandemic); NASHP Appendix K Map, *supra* note 86 (providing an interactive map of the United States with a "services" tab to track each state's recent changes to HCBS); KFF COVID-19 Tracker, *supra* note 86 (categorizing each state's approved Section 1915(c) waivers to address COVID-19 as they expand eligibility, services, service planning and delivery, settings, providers, oversight, and cost sharing).

133. Edwards, *supra* note 9, at 4, 13.

delivery.¹³⁴ Comparatively, states have made fewer changes to behavioral health services.¹³⁵ However, some states, like Arkansas, have added new behavioral health optional services called “management and evaluation” to check on individuals either telephonically or in their home to assist individuals with “serious mental illness” who are unable to attend regular service programs.¹³⁶

2. Supporting Community-Living Through Expanding Access to Medications

Access to medication is essential to all Medicaid enrollees, but particularly for individuals with disabilities, who typically have greater need for prescription drugs and have well-documented health disparities.¹³⁷ For many different kinds of disabilities the standard of care involves medication – including antiretroviral therapy for a person with HIV; antipsychotic medications as part of treatment for schizophrenia; and medications such as methadone and buprenorphine for opioid use disorder.¹³⁸ The pandemic has affected supply chains for those

134. See, e.g., *Adult Day Services Provided During the COVID-19 Emergency FAQ*, *supra* note 53.

135. Edwards, *supra* note 9, at 3, 12 (discussing how individualized services, particularly those that require direct service workers, may be halted because of the pandemic and highlighting how common themes in approved Appendix Ks focus on topics such as rate flexibility, waiving provider qualifications, and lifting respite limits, rather than on behavioral health).

136. ARK. DEP’T OF HUM. SERVS., AR-20-0016, ARKANSAS STATE PLAN AMENDMENT (SPA) 20-0016 (2020) (adding a fifteen- to thirty-minute telephonic or in-person “check-in” for the 1915(i) program). See also EXEC. OFF. OF HEALTH & HUM. SERVS. STATE OF R.I., RI-20-0007, RHODE ISLAND STATE PLAN AMENDMENT (SPA) 20-0007 (2020) (creating “emergency case management” services for certain individuals to prevent exposure to COVID-19, to assist individuals who need to quarantine or have tested positive, and to connect individuals to services to address “health-related social needs (e.g., food insecurity, transportation) that may have been exacerbated by the COVID-19 pandemic.”)

137. See, e.g., *Disability and Health Data System*, CTRS. FOR DISEASE CONTROL & PREVENTION (2017), <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html> (Select “general health conditions” from the dropdown menu; then select “taking medication for high blood pressure” from the dropdown menu; and then select “no disability” from the dropdown menu to see nationwide statistics. For breakdowns by ethnicity, select “any disability” and “race/ethnicity” from the dropdown menus.) (noting that 57.7% of adults with disabilities take medication for high blood pressure, compared to 42.3% for adults without disabilities; for Black adults with disabilities, the number is even higher, at 71.1%, and 61% for Hispanic adults with disabilities).

138. Corey Davis et al., *Medication-Assisted Treatment for Opioid Use Disorder: The Gold Standard*, NAT’L HEALTH L. PROGRAM 1, 2 (2018), <https://healthlaw.org/resource/medication-assisted-treatment-for-opioid-use-disorder-the-gold-standard/>. See AM. PSYCHIATRY ASS’N, THE AMERICAN PSYCHIATRIC ASSOCIATION PRACTICE GUIDELINE FOR THE TREATMENT OF PATIENTS WITH SCHIZOPHRENIA 1, 23 (2020) (detailing the recommendation that patients with schizophrenia have a treatment plan that includes both evidence-based pharmacological and non-pharmacological treatments); PANEL ON ANTIRETROVIRAL GUIDELINES FOR ADULTS & ADOLESCENTS, U.S. DEP’T HEALTH & HUM. SERVS., GUIDELINES FOR THE USE OF ANTIRETROVIRAL AGENTS IN ADULTS AND ADOLESCENTS LIVING WITH HIV ii (2019) (discussing how antiretroviral therapy must be

prescription drugs.¹³⁹ Furthermore, at a time when access to medication to manage chronic conditions has been more important than ever, people need to limit their interactions with one another, including visits to stores and pharmacies.¹⁴⁰

Prior to COVID-19, many state Medicaid agencies and managed care organizations imposed restrictive access policies on many prescription medications, including preferred drug lists, prior authorization, frequent refill requirements, and other policies that steer individuals toward some drugs over others or limit access.¹⁴¹ For example, forty-one states required enrollees to use generic drugs that are equivalent to brand names, and others imposed quantitative limits on the number of prescriptions an enrollee can access per month, or limits on the frequency of refills.¹⁴² These restrictions harmed people with disabilities. For individuals with psychiatric disabilities such as schizophrenia and bipolar disorder, prior authorization requirements have been associated with medication discontinuation, reduction in visits to community mental health centers, and increases in emergency room visits.¹⁴³ Similarly, caps

started immediately or as soon as possible after an HIV diagnosis in order to achieve virologic suppression and reduce transmission risk).

139. Lovisa Gustafsson, *COVID-19 Highlights Problems with Our Generic Supply Chain*, COMMONWEALTH FUND (May 7, 2020), <https://www.commonwealthfund.org/blog/2020/covid-19-highlights-problems-our-generic-supply-chain>.

140. *See id.* (detailing an increase in patients' demand for more prescription medications than usual, similar to the hoarding and stockpiling of other essentials, such as toilet paper).

141. *See* 42 C.F.R. § 440.230(d) (2020). All states opt to provide prescription outpatient drugs. *Prescription Drugs*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.medicaid.gov/medicaid/prescription-drugs/index.html> (last visited Jan. 2, 2021). 42 U.S.C. § 1396d(a)(12). 42 C.F.R. §§ 440.120(a), .90, .100. Once a state elects to cover outpatient prescription drugs, it generally must cover all drugs approved by the U.S. Food and Drug Administration (FDA) that are offered by any manufacturer that agrees to provide rebates. 42 U.S.C. § 1396r-8(k)(2)(A). *See also Prescription Drugs*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, <https://www.macpac.gov/topics/prescription-drugs/> (last visited Jan. 2, 2021) (describing the Medicaid Drug Rebate Program). A preferred drug list is a list of drugs that the state encourages providers to prescribe over other medications, and prior authorization is a requirement that you receive approval from your insurer prior to obtaining a medication. *See* Abbi Coursolle, *Utilization Controls for Medicaid Prescription Drugs*, NAT'L HEALTH L. PROGRAM 1, 5 (2016), <https://healthlaw.org/wp-content/uploads/2016/12/113016-Rx-Guide-Utilization-Requirement-for-Covered-Rx-FINAL.pdf> (detailing covered outpatient drug utilization controls).

142. Prior to March 2020, most state Medicaid programs commonly used several drug benefit utilization controls. Almost all states used preferred drug lists and prior authorization. Kathleen Gifford et al., *How State Medicaid Programs Are Managing Prescription Drug Costs Results from a State Medicaid Pharmacy Survey for State Fiscal Years 2019 and 2020*, KAISER FAM. FOUND. 3, 14, 17–18 (2020), <http://files.kff.org/attachment/How-State-Medicaid-Programs-are-Managing-Prescription-Drug-Costs.pdf>. *See also* Coursolle, *supra* note 141.

143. Christine Y. Lu et al., *Association Between Prior Authorization for Psychiatric Medications and Use of Health Services Among Medicaid Patients with Bipolar Disorder*, 62 PSYCHIATRIC SERVS. 186, 192 (2011).

on the number of prescriptions per month without generous overrides have been associated with high levels of untreated mental health issues for individuals with bipolar disorder, and moves to more generous prescription drug coverage are associated with increases in treatment.¹⁴⁴ For some individuals prescribed atypical antipsychotics, preferred drug lists are associated with fewer days of medication coverage in a 365-day period and increased risk of hospitalization.¹⁴⁵

In response to COVID-19, some states have temporarily amended their state plans to loosen these restrictions.¹⁴⁶ Many states have relaxed refill requirements, permitting Medicaid enrollees to get up to a 102-day supply of medication, suspended prior authorization requirements, and allowed exceptions to the preferred drug list to allow for brand name medications when generic medications are not available.¹⁴⁷ Approximately half the states have eliminated cost sharing, with some specifically limiting this change to prescription medications and others doing so across the board.¹⁴⁸ States have also received approval to change their state plans to permit early refills, and have increased reimbursement to cover increased costs related to delivery of medication.¹⁴⁹

144. Jeanne M. Madden et al., *Changes in Drug Coverage Generosity and Untreated Serious Mental Illness: Transitioning from Medicaid to Medicare Part D*, 72 JAMA PSYCHIATRY 179, 182 (2015).

145. Seth A. Seabury et al., *Formulary Restrictions on Atypical Antipsychotics: Impact on Costs for Patients with Schizophrenia and Bipolar Disorder in Medicaid*, 20 AM. J. MANAGED CARE e52, e55–58 (2014), <https://cdn.sanity.io/files/0vv8moc6/ajmc/3314deeb6512c56ac3ad03186dc05ddb11db44c4.pdf>.

146. For example, Oregon requested and received approval to temporarily change its state plan, justifying this change based on exposure risk: “OHA is allowing DXC [Oregon claims contractor] to exercise clinical judgment to waive day supply limits when appropriate to reduce exposure risk.” OR. HEALTH AUTH., OR-20-0010, OREGON STATE PLAN AMENDMENT (SPA) 20-0010 (2020).

147. *E.g.*, Michigan requested and received approval for an upper limit of 102-day supply for medications. MED. SERVS. ADMIN., MI-20-0005, MICHIGAN STATE PLAN AMENDMENT (SPA) 20-0005 (2020). Likewise, California received approval to supply 100 days, as well as to waive its six medications per month limit. CAL. DEP’T OF HEALTH CARE SERVS., CA-20-0024, CALIFORNIA STATE PLAN AMENDMENT (SPA) 20-0024 (2020). For a general overview of the different Medicaid emergency authorities and charts of state changes under each, see Alexia Gardner, *Approved 1135 Waivers and State Plan Amendments for COVID-19*, GEO. UNIV. HEALTH POL’Y INST. (Mar. 24, 2020), <https://ccf.georgetown.edu/2020/03/24/approved-1135-waivers/>.

148. KFF COVID-19 Tracker, *supra* note 86.

149. For examples of approved state plan amendments that allow early refills, see MONT. DEP’T OF PUB. HEALTH & HUM. SERVS., MT-20-0024, MONTANA STATE PLAN AMENDMENT (SPA) 20-0024 (2020); OR. HEALTH AUTH., OR-20-0010, OREGON STATE PLAN AMENDMENT (SPA) 20-0010 (2020); N.J. DEP’T OF HUM. SERVS., NJ-20-0003, NEW JERSEY STATE PLAN AMENDMENT (SPA) 20-0003 (2020); and VA. DEP’T OF MED. ASSISTANCE SERVS., VA-20-0010, VIRGINIA STATE PLAN AMENDMENT (SPA) 20-0010 (2020). For an example of a state enabling a “payment adjustment to the professional dispensing fee when additional costs are incurred by the providers for delivery,” see EXEC. OFF. OF HEALTH & HUM. SERVS., MA-20-0007, MASSACHUSETTS STATE PLAN AMENDMENT (SPA) 20-0007 (2020).

3. Removing Barriers to Substance Use Disorder Treatment

People who rely on HCBS for substance use disorder (SUD) treatment, including for medication, face an additional set of barriers related to access to treatment during COVID-19. Medication is an integral part of treatment for some substance use disorders, particularly opioid use disorder (OUD), and medication-assisted treatment is a mandatory service under Medicaid.¹⁵⁰ States must cover the three main types of medications for opioid use disorders (MOUDs): buprenorphine, naltrexone, and methadone.¹⁵¹ Despite this mandatory coverage, layers of additional laws and regulations circumscribing access to MOUDs have created high barriers to treatment.¹⁵² COVID-19 has made already difficult barriers even more challenging.

Prior to the pandemic, the majority of states subjected MOUDs to prior authorization requirements and quantity limits.¹⁵³ Many states also limited naloxone, a medication that reverses the effects of an opioid overdose and can save lives.¹⁵⁴ Therefore, state Medicaid emergency waivers to make prescription drugs easier to obtain and disaster state plan amendments to relax utilization controls increase access to buprenorphine, naltrexone, and naloxone, which are included in the definition of outpatient medication covered by Medicaid.¹⁵⁵

150. Letter from Anne Marie Costello, Acting Deputy Adm'r & Dir., Ctrs. for Medicare & Medicaid Servs., to State Health Offs. 1, 17 (Dec. 30, 2020), <https://www.medicaid.gov/federal-policy-guidance/downloads/sho20005.pdf>. The mandate to cover methadone is only for five years. See 42 U.S.C. §§ 1396a(10)(A), 1396d(a)(29), 1396d(ee). Buprenorphine and naltrexone will likely continue to be covered by all states beyond the five-year mandate because they are also classified as an outpatient drug pursuant to 42 U.S.C. § 1396-r8.

151. Letter from Anne Marie Costello, *supra* note 150, at 2.

152. U.S. SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., MEDICAID COVERAGE OF MEDICATION-ASSISTED TREATMENT FOR ALCOHOL AND OPIOID USE DISORDERS AND OF MEDICATION FOR THE REVERSAL OF OPIOID OVERDOSE 3 (2018).

153. *Id.* at 2, 91–92. According to a study by the Substance Abuse and Mental Health Services Administration (SAMHSA), for buprenorphine during 2016–2017, all states covered the medication, but twenty-one states did not have it on the preferred drug list, and forty states required prior authorization.

154. *Medicaid Behavioral Health Services: Naloxone Available in at Least One Formulation Without Prior Authorization*, KAISER FAM. FOUND. nn.3–14 (2018), <https://www.kff.org/other/state-indicator/medicaid-behavioral-health-services-naloxone-available-in-at-least-one-formulation-without-prior-authorization/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (noting that while at least forty-six states cover at least one formulation of naloxone without prior authorization, at least nine states impose other utilization limits on the drug); *U.S. Surgeon General's Advisory on Naloxone and Opioid Overdose*, OFF. OF THE SURGEON GEN., U.S. DEP'T. OF HEALTH & HUM. SERVS., <https://www.hhs.gov/surgeon-general/priorities/opioids-and-addiction/naloxone-advisory/index.html> (last updated Apr. 5, 2018) (citing the life-saving importance of access to naloxone by users of opioids and those around them).

155. Jessica Schubel, *States Are Leveraging Medicaid to Respond to COVID-19*, CTR. BUDGET & POL'Y PRIORITIES 3 (2020), <https://www.cbpp.org/research/health/states-are-leveraging-medic-aid-to-respond-to-covid-19>; see generally 42 U.S.C. § 1396d(ee)(1).

Unlike other medications, MOUDs are subject to additional federal controls.¹⁵⁶ These regulations and restrictions exist apart from whether an individual uses private insurance, Medicaid, or other sources of payment for these services.¹⁵⁷ For example, health professionals must receive a federal “waiver” to prescribe buprenorphine at all, and even with a waiver they may only treat a limited number of individuals.¹⁵⁸ Additionally, providers generally must conduct a face-to-face visit with a patient before they can prescribe buprenorphine, which poses a significant barrier even in normal times, particularly for individuals in rural areas and those without reliable transportation.¹⁵⁹ Such limitations combine to reduce the number of providers who can prescribe the medication, and this reduction has a particularly harsh impact on access to SUD treatment for Black adults. For example, “despite similar prevalence of OUD among Black and White adults, from 2012 to 2015 White patients were almost 35 times more likely to have a buprenorphine-related office visit compared to Black patients . . .”¹⁶⁰ During the pandemic, the Drug Enforcement Agency (DEA) has permitted buprenorphine initiation via telephone and has waived the requirement for providers to obtain a separate registration in each state in which they practice.¹⁶¹ Waiving the requirement for

156. *See generally* JENNIFER BERNSTEIN ET AL., A CROSS-SECTOR APPROACH TO REMOVING LEGAL AND POLICY BARRIERS TO OPIOID AGONIST TREATMENT, NETWORK FOR PUB. HEALTH L. (2020).

157. *Id.* at 9.

158. 21 U.S.C. § 823(g); Practice Guidelines for the Administration of Buprenorphine for Treating Opioid Use Disorder, 86 Fed. Reg. 22439 (Apr. 28, 2021).

159. 21 U.S.C. § 829(e). *See also* *Opioid Use Disorder: Challenges and Opportunities in Rural Communities: Thoughtful Strategies Can Improve Access to High-Quality Care*, PEW CHARITABLE TRUST (Feb. 7, 2019), <https://www.pewtrusts.org/en/research-and-analysis/fact-sheets/2019/02/opioid-use-disorder-challenges-and-opportunities-in-rural-communities> (describing the shortage of buprenorphine prescribers in rural areas and the increased need for individuals with SUD to travel for treatment and rely on friends and family for transportation); Stacey C. Sigmon, *Access to Treatment for Opioid Dependence in Rural America Challenges and Future Directions*, 71 JAMA PSYCHIATRY 359 (2014).

160. Corey S. Davis & Amy Judd Lieberman, *Access to Treatment for Individuals with Opioid Use Disorder*, in ASSESSING LEGAL RESPONSES TO COVID-19, at 134 (Scott Burris et al. eds., 2020), https://static1.squarespace.com/static/5956e16e6b8f5b8c45f1c216/t/5f445d4ff0e1b42d8e2bfcad/1598315855348/Chp17_COVIDPolicyPlaybook-Aug2020.pdf.

161. *Compare* 21 U.S.C. § 802(54)(D) and 21 C.F.R. § 1307.03 (2020) (allowing any person to request an exemption from any provision in the rules implementing the Controlled Substances Act by filing a written request with the Office of Diversion Control, Drug Enforcement Agency), with Letter from Thomas Prevoznik, Deputy Assistant Adm’r, Diversion Control Div., U.S. Dep’t of Just., to DEA Registrants (Mar. 31, 2020) (on file with U.S. Dep’t of Just.); Letter from William McDermott, Assistant Adm’r, Diversion Control Div., U.S. Dep’t of Just., to DEA Registrants (Mar. 25, 2020) (on file with U.S. Dep’t of Just.). *See also* Corey S. Davis & Elizabeth A. Samuels, *Continuing Increased Access to Buprenorphine in the United States via Telemedicine After COVID-19*, INT’L J. DRUG POL’Y, 2 (Aug. 15, 2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7428767/#bib0019> (discussing treatment via telehealth).

an office visit could improve access to MOUD generally, and particularly for Black adults, given the racial disparities in access to buprenorphine-related office visits. However, as discussed in the next section, for such a strategy to be effective, racial disparities in access to telehealth must also be addressed.¹⁶²

Methadone's federal restrictions may be even more pronounced. Generally, only licensed, certified opioid treatment programs (OTP) may administer methadone.¹⁶³ Unlike buprenorphine, beneficiaries cannot initiate Methadone treatment via telehealth during the public health emergency.¹⁶⁴ Nor can states simply amend their Medicaid state plans to provide a larger supply of medication.¹⁶⁵ "Take-home" doses are permissible, but prior to the pandemic, two weeks' worth of methadone was limited to people enrolled in an OTP for at least a year, and one month of take-home medication was limited to those enrolled two years.¹⁶⁶ In response to the pandemic, federal guidance now permits twenty-eight days of take-home doses for all stable patients, and fourteen days for those who are less stable, but whom the OTP deems able to safely handle take-home doses.¹⁶⁷ This flexibility allows many more individuals to avoid daily travel to a clinic. Though temporary, these changes could be made permanent via legislation or regulatory changes.¹⁶⁸

4. The Growth of Telehealth

States have provided additional pathways to services during the pandemic by expanding coverage of telehealth.¹⁶⁹ Previously, telehealth policies limited

162. *Infra* Section III.B.4.

163. 42 C.F.R. § 8 (2020).

164. *FAQs: Provision of Methadone and Buprenorphine for the Treatment of Opioid Use Disorder in the COVID-19 Emergency*, U.S. SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN. 1 (Apr. 21, 2020), <https://www.samhsa.gov/sites/default/files/faqs-for-oud-prescribing-and-dispensing.pdf>.

165. 21 C.F.R. § 1301.74(k) (2020); 42 C.F.R. § 8.12(h) (2020).

166. 42 C.F.R. § 8.12(i) (2020).

167. SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., U.S. DEP'T. OF HEALTH & HUMAN SERVS., OPIOID TREATMENT PROGRAM (OTP) GUIDANCE (2020).

168. Davis & Samuels, *supra* note 161, at 2–3 (discussing permanently reducing barriers to buprenorphine).

169. *See COVID-19 Related State Actions*, CTR. FOR CONNECTED HEALTH POL'Y, <https://www.fsmb.org/siteassets/advocacy/pdf/states-waiving-licensure-requirements-for-tele-health-in-response-to-covid-19.pdf> (last visited Nov. 9, 2020) (tracking emergency-based telehealth changes in state Medicaid programs); Gabriela Weigel et al., *Opportunities and Barriers for Telemedicine in the U.S. During the COVID-19 Emergency and Beyond*, KAISER FAM. FOUND. (2020), <https://www.kff.org/womens-health-policy/issue-brief/opportunities-and-barriers-for-tele-medicine-in-the-u-s-during-the-covid-19-emergency-and-beyond/>; *see also* Fabiola Carrion, *Top Ten List: Telehealth Coverage During COVID-19*, NAT'L HEALTH L. PROGRAM 1 (May 18, 2020), <https://healthlaw.org/resource/top-ten-list-telehealth-coverage-during-covid-19/> [hereinafter *Telehealth Coverage*]; *State Data and Policy Actions to Address Coronavirus*, KAISER FAM. FOUND., <https://www.kff.org/coronavirus-covid-19/issue-brief/state-data-and-policy-actions-to-ad>

who could provide services, the location of the recipient and the provider, and the range of services that could be provided.¹⁷⁰ Also, provider payment rates for services delivered via telehealth were typically lower than for comparable in-person services.¹⁷¹ Many states also restricted the method of providing telehealth to live videoconferencing, leaving out modalities like remote patient monitoring, telephone-based visits, e-consults between providers, and services via a variety of electronic chat methods.¹⁷² State Medicaid agencies rapidly shifted from covering very limited telehealth to allowing telehealth options, or hybrid telehealth/home visit models, for a large variety of services.¹⁷³ This expansion applied to HCBS, including adult day, personal care, and services such as physical and occupational therapy, behavioral health, and SUD.¹⁷⁴ States also allowed telehealth for person-centered planning meetings and assessments.¹⁷⁵

dress-coronavirus/ (summarizing state actions on telehealth); *see generally* Fabiola Carrion, *Medicaid Principles on Telehealth*, NAT'L HEALTH L. PROGRAM (2020), <https://healthlaw.org/resource/medicaid-principles-on-telehealth/> (outlining a list of principles states should consider when making policy decisions around telehealth).

170. *See* Madeline Guth & Elizabeth Hinton, *Coverage & Access to Telehealth in Response to COVID-19*, KAISER FAM. FOUND. (June 22, 2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/state-efforts-to-expand-medicare-coverage-access-to-telehealth-in-response-to-covid-19>.

171. *See* CTR. FOR CONNECTED HEALTH POL'Y, STATE TELEHEALTH LAWS & REIMBURSEMENT POLICIES 11 (2020); *Telehealth Coverage*, *supra* note 169.

172. CTR. FOR CONNECTED HEALTH POL'Y, *supra* note 171, at 7–8; *Telehealth Coverage*, *supra* note 169, at 2.

173. *Telehealth Coverage*, *supra* note 169, at 2; *COVID-19 Related State Actions*, CTR. FOR CONNECTED HEALTH POL'Y, cchpca.org/covid-19-related-state-actions (last visited Jan. 23, 2021).

174. Guth & Hinton, *supra* note 170.

175. All states used Appendix K to allow virtual evaluations, assessments, and person-centered planning. KFF COVID-19 Tracker, *supra* note 86 (noting all states but Alaska, but a check of Alaska Appendix K shows the approval of telephonic contact to determine level of care and remote renewal of plan of care). *See also* David Machledt & Elizabeth Edwards, *Home-Based Care Under COVID-19: A Do No Harm Approach to Assessing Needs*, NAT'L HEALTH L. PROGRAM BLOG (May 12, 2020), <https://healthlaw.org/home-based-care-under-covid-19-a-do-no-harm-approach-to-assessing-needs/>. Alexis Robles-Fradet & Abigail Coursolle, *Medicaid Offers Critical Support for People Who Are Experiencing Behavioral Health Crises During the COVID-19 Pandemic*, NAT'L HEALTH L. PROGRAM BLOG (May 29, 2020), <https://healthlaw.org/medicaid-offer-critical-support-for-people-who-are-experiencing-behavioral-health-crises-during-the-covid-19-pandemic/>; *see also, e.g.*, NEB. DEP'T HEALTH & HUM. SERVS., NE-20-0010, NEBRASKA STATE PLAN AMENDMENT (SPA) NE-20-0010 (2020) (allowing telephonic evaluation and management for enrollees requiring behavioral health assessment and management, and permitting community support services via two-way, real time, audio-visual services). Other states have eliminated face-to-face requirements for certain behavioral health services, enabling those providers to deliver the services telephonically. GA. DEP'T CMTY. HEALTH, GA-20-0006, GEORGIA STATE PLAN AMENDMENT (SPA) 20-0006 (2020); MICH. MED. SERVS. ADMIN., MI-20-0005, MICHIGAN STATE PLAN AMENDMENT (SPA) 20-0005 (2020); MINN. DEP'T OF HUM. SERVS., MN-20-0004, MINNESOTA STATE PLAN AMENDMENT (SPA) 20-0004 (2020); OR. HEALTH AUTH., OR-20-0011,

During the pandemic, the significant expansion of coverage of telehealth services has greatly increased access to care. But this reliance on telehealth as a primary access solution may exacerbate existing disparities. Although states rapidly expanded telehealth, much of this expansion was focused on telehealth modalities that require high speed internet and video technology, and the use of telephone only or other methods was less common.¹⁷⁶ The focus on expansion of video-based telehealth meant that a significant proportion of Medicaid households could not access telehealth due to a lack of internet access at a time when the demand for telehealth soared due to the pandemic.¹⁷⁷ Nearly one-third of households in the United States lack a broadband connection, with most of those households being in rural areas, often due to the cost of the service and lack of options.¹⁷⁸ The lack of reliable and affordable internet has been tied to not only economic development, but also to digital red-lining and the lack of infrastructure linked to institutional racism.¹⁷⁹ For example, more than thirty

OREGON STATE PLAN AMENDMENT (SPA) 20-0011 (2020) (expanding access to behavioral health services via telehealth through approved SPAs).

176. Prior to the pandemic, although all states and DC allowed some telehealth services, it was largely restricted to live video. Weigel et al., *supra* note 169. *See, e.g., COVID-19 Related State Actions*, *supra* note 169 (tracking that telephonic/audio-only delivery is often only available, if at all, for specific services).

177. Weigel et al., *supra* note 169.

178. *Thirty-One Percent of U.S. Households Lack a Broadband Connection*, THE NPD GROUP (July 25, 2019), <https://www.npd.com/wps/portal/npd/us/news/press-releases/2019/thirty-one-percent-of-u-s-households-lack-a-broadband-connection/>; Dena H. Jaffe et al., *Health Inequalities in the Use of Telehealth in the United States in the Lens of COVID-19*, 23(5) POPULATION HEALTH MGMT. 368, 375 (2020) (finding that the southern United States has lower telehealth usage and lower median household income). *See also* FED. COMM'NS COMM'N, 2019 BROADBAND DEPLOYMENT REPORT 2 (2019). *But see* Linda Poon, *There Are Far More Americans Without Broadband Access Than Previously Thought*, BLOOMBERG CITYLAB (Feb. 19, 2020), <https://www.bloomberg.com/news/articles/2020-02-19/where-the-u-s-underestimates-the-digital-divide> (discussing report that found the FCC report vastly underestimated access to broadband).

179. *See On the Wrong Side of the Digital Divide*, GREENLINING (June 2, 2020), https://greenlining.org/publications/online-resources/2020/on-the-wrong-side-of-the-digital-divide/?utm_source=sendgrid&utm_medium=email&utm_campaign=Newsletters (drawing the connection through mapping between access to the internet and redlining); Betsy Lawton, *Assessing Efforts to Ensure Equitable Access to Broadband Services that Support Public Health*, NETWORK FOR PUB. HEALTH L. (Oct. 8, 2020), <https://www.networkforphl.org/news-insights/assessing-efforts-to-ensure-equitable-access-to-broadband-services-that-support-public-health/> (discussing digital redlining and racial disparities in access to broadband); *see, e.g.*, Bill Callahan, *AT&T's Digital Redlining of Dallas: New Research by Dr. Brian Whitacre*, NAT'L DIGIT. INCLUSION ALL. (Aug. 6, 2019), <https://www.digitalinclusion.org/blog/2019/08/06/atts-digital-redlining-of-dallas-new-research-by-dr-brian-whitacre/> (“AT&T has withheld fiber-enhanced broadband improvements from most Dallas neighborhoods with high poverty rates, relegating them to Internet access services which are vastly inferior to the services enjoyed by their counterparts nearby in the higher-income Dallas suburbs.”); *see also* Nicole Dozier & William H. Munn, *Historical Geography and Health Equity*, 81(3) N.C. MED. J. 198, 199 (May 4, 2020) (drawing connections between present day

percent of Latinx or Black children have no computer at home, more than twice the rate for White children (fourteen percent).¹⁸⁰ In addition, while nearly one-third of low-income Americans rely on smartphones with data plans for internet access, roughly three-in-ten adults in lower income households do not own a smartphone.¹⁸¹ Households with individuals covered by Medicaid are also less likely to have broadband access.¹⁸² Households that include a person with a disability, which are more prevalent in rural areas, are also less likely to have access to broadband.¹⁸³

Audio-only telehealth is also inaccessible for many low-income individuals. Medicaid households are eligible for, and many use, the government funded Lifeline program for telephone and internet access.¹⁸⁴ Many use the Lifeline program to access cell phone plans with limited minutes and data (e.g., 250 voice minutes and 2GB of mobile data).¹⁸⁵ However, prior to the pandemic, the Trump administration made significant program changes that limited providers and made eligibility more difficult to verify, causing the program to shrink by forty

sociohealth outcomes, including a discussion of infrastructure, and the prevalence of slavery in North Carolina).

180. David Velasquez & Ateev Mehrotra, *Ensuring the Growth of Telehealth During COVID-19 Does Not Exacerbate Disparities in Care*, HEALTH AFFS. BLOG (May 8, 2020), <https://www.healthaffairs.org/doi/10.1377/hblog20200505.591306/full/> (finding that digital literacy is much lower for older people of color and for people with less education).

181. Monica Anderson & Madhumitha Kumar, *Digital Divide Persists Even as Lower-Income Americans Make Gains in Tech Adoption*, PEW RSCH CTR.: FACTTANK (May 7, 2019), <https://www.pewresearch.org/fact-tank/2019/05/07/digital-divide-persists-even-as-lower-income-americans-make-gains-in-tech-adoption/>. In addition to not many adults in lower-income households owning a smartphone, a similar percentage of such adults (twenty-six percent) are smartphone-dependent internet users, meaning that they own a smartphone but do not have internet access at home. *Id.*

182. *Internet Access Measures the Impact of the Digital Divide and COVID-19*, STATE HEALTH ACCESS DATA ASSISTANCE CTR. (Mar. 27, 2020), <https://www.shadac.org/news/internet-access-measures-impact-digital-divide-and-covid-19#:~:text=Nationally%2C%20households%20that%20included%20someone,86.9%20percent> (showing that nationally, households that included someone enrolled in Medicaid were nine percent less likely to have broadband access, with this difference greater in certain areas).

183. *Id.*; *Prevalence of Disability and Disability Types by Urban-Rural Classification-Unites States, 2016*, CTRS. FOR DISEASE CONTROL & PREVENTION (Sept. 16, 2020), <https://www.cdc.gov/ncbddd/disabilityandhealth/features/disability-prevalence-rural-urban.html> (also discussing findings that show that the percentage of adults having at least four of five health-related behaviors is lowest in rural counties).

184. See Jared Bennett & Ashley Wong, *Millions of Poor Lose Access to Cellphone Service Under Trump Administration Reforms*, USA TODAY (Nov. 7, 2019), <https://www.usatoday.com/story/news/investigations/2019/11/05/under-trump-millions-poor-lose-cellphone-service/2482112001/>.

185. *Id.*

percent.¹⁸⁶ While the Federal Communications Commission (FCC) temporarily waived recertification and other requirements to help individuals keep and access Lifeline services during the pandemic, by that time only a fifth of eligible households were still participating and many were not impacted by the FCC's Keep Americans Connected pledge.¹⁸⁷ Households that rely on Lifeline cell phones for communication and internet access may not have enough minutes or data available to participate in telehealth, regardless of modality.

Access to telehealth requires more than just internet access, it also requires the ability to use technology and access to the necessary devices. People with lower incomes, older adults, and people of color are more likely to experience the three most common barriers to telehealth usage: absence of technology, digital literacy, and reliable internet; this combination is known as the "digital divide."¹⁸⁸ For example, if a state only expanded the types of Medicaid services that could be provided through telehealth, but not the modalities, it likely only expanded access unevenly to a limited group that skews toward younger, more urban residents who readily use technology and have the necessary devices and internet.¹⁸⁹ While a few states used pandemic-related Medicaid flexibilities to expand coverage of assistive technology necessary for telehealth, this was often limited to 1915(c) waiver participants.¹⁹⁰ Importantly, providing the equipment does not fully address the lack of training, internet access, or accessibility of the telehealth method or device.

Even if the equipment is provided and training is available, telehealth still may remain out of reach for people with disabilities. Despite the ADA being thirty years old, not all telehealth is accessible. For example, not all video

186. *Id.* See also Gigi Sohn, *During the Pandemic, the FCC Must Provide Internet for All*, WIRED (Apr. 28, 2020), <https://www.wired.com/story/opinion-during-covid-19-the-fcc-needs-to-provide-internet-for-all/>; Lawton, *supra* note 179.

187. *Lifeline Support for Affordable Communications*, FED. COMM'NS COMM'N, (Sept. 14, 2020), <https://www.fcc.gov/lifeline-consumers>; Sohn, *supra* note 186 (citing that Lifeline serves only twenty percent of eligible households); *Companies Have Gone Above and Beyond the Call to Keep Americans Connected During Pandemic*, FED. COMM'NS COMM'N (Oct. 14, 2020), <https://www.fcc.gov/companies-have-gone-above-and-beyond-call-keep-americans-connected-during-pandemic>.

188. Velasquez & Mehrotra, *supra* note 180. See also Michelle W. Katzow et al., *Telemedicine and Health Disparities During COVID-19*, PEDIATRICS, Aug. 2020, at 1, 1–2 (finding that lower-income adults are less likely to have access to a computer or to use email, as well as highlighting the need for alternative platforms for telemedicine such as applications like Whatsapp).

189. Katzow et al., *supra* note 188, at 1–2; CTR. FOR CONNECTED HEALTH POL'Y, *supra* note 170, at 3.

190. See, e.g., CONN. DEP'T OF SOC. SERVS., CT-20-0015, CONNECTICUT STATE PLAN AMENDMENT (SPA) 20-0015 (2020) (lifting the existing limit of \$1000 for assistive technology in its 1915(i) state plan HCBS); ALA. MEDICAID AGENCY, ID 0001.R08.03, LAH 0391.03.03, APPENDIX K: EMERGENCY PREPAREDNESS AND RESPONSE (2020) (allows a specific request to be made for assistive technology, including iPad style tablets or other devices needed to access virtual services as long as appropriate to the individual's needs).

conferencing platforms allow for live closed captioning or American Sign Language (ASL) interpretation, nor are all compatible with screen readers or assistive devices.¹⁹¹ In addition, certain applications used for telehealth, especially remote monitoring, may not be fully accessible or people with disabilities may not have access to the technology necessary to use those applications.¹⁹² Before the pandemic, people with disabilities had relatively low rates of computer ownership, but were increasingly the users of telehealth.¹⁹³ Thus, accessibility in telehealth must not be an afterthought to either telehealth policies or technologies.

For people with disabilities, telehealth also presents opportunities. Telehealth “promises reduced adverse health outcomes, care coordination needs, and may even reduce risk of long-term hospitalization or institutionalization.”¹⁹⁴ It could sharply lessen the burden of accessing care for people with disabilities, such as the time and physical burdens of going to an appointment which may or may not be accessible.¹⁹⁵ These challenges are not unique to people with physical disabilities, as leaving home and navigating the complexities, people, and sensory inputs of hospitals or similar busy settings are required for most clinical visits, and may affect people with other types of disabilities.¹⁹⁶ Therefore, the pandemic-based expansion of telehealth helps many people with disabilities by not only providing access to care without having to risk going to a site, but may continue to make accessing care easier if the telehealth-related changes remain after the pandemic.

The disparities in who would benefit from expanded telehealth were not unexpected, and increasing reliance on telehealth as a solution to access to care

191. See Thiru M. Annaswamy et al., *Telemedicine Barriers and Challenges for Persons with Disabilities: COVID-19 and Beyond*, 13 DISABILITY & HEALTH J. 1, 2 (2020); see also George M. Powers et al., *Telemedicine: Access to Health Care for People with Disabilities*, 17 HOUS. J. HEALTH L. & POL’Y 7, 14–15 (2017).

192. Annaswamy et al., *supra* note 191. For example, some people with intellectual disabilities may have difficulty with effective communication through telehealth and people with mobility or manual dexterity disabilities may experience problems with the virtual interface or device. *Id.*

193. Kimberly Noel & Brooke Ellison, *Inclusive Innovation in Telehealth*, NATURE PARTNER J. DIGIT. MED., June 25, 2020, at 1, 1. “Between 2014 and 2016, there was a 37.7% increase in the number of beneficiaries with disabilities using telehealth, and a 53.7% increase in the total services these beneficiaries used,” and “in 2016, persons with disabilities accounted for 65% (58,406) of beneficiaries using telehealth, using over 66% (182,858) of all telehealth services” with particularly high utilization among those eligible for Medicare under the age of 65 (based on disability). *Id.*

194. *Id.*

195. Daniel Young & Elizabeth Edwards, *Telehealth and Disability: Challenges and Opportunities for Care*, NAT’L HEALTH L. PROGRAM (May 6, 2020), <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>; Annaswamy et al., *supra* note 191, at 2.

196. Young & Edwards, *supra* note 195.

issues may create greater access issues.¹⁹⁷ While telehealth use skyrocketed in comparison to pre-pandemic numbers, one study found that White patients had higher adjusted odds of using telehealth than Black patients.¹⁹⁸ In addition, lower mean income and larger mean household size were associated with lower likelihood of telehealth use.¹⁹⁹ Similarly, initial data on telehealth usage in Medicaid in one state showed disproportionately high usage of telehealth by White beneficiaries as compared to their relative share of the state's Medicaid population, regardless of the telehealth modality.²⁰⁰ Compounding the disproportionate impact of telehealth providing care to only a subset of the population, many of those excluded from improved telehealth access were the same populations at higher risk of both contracting COVID-19 and experiencing adverse side effects.²⁰¹

IV. RECOMMENDATIONS & CONCLUSION

A. Recommendations

The COVID-19 pandemic generated rapid changes in state Medicaid programs. Not all of these changes should be abandoned when the public health emergency ends. States should evaluate the range of pandemic-based problem-

197. Rumi Chunara et al., *Telemedicine and Healthcare Disparities: A Cohort Study in a Large Healthcare System in New York City During COVID-19*, 28 J. AM. MED. INFORMATICS ASS'N 33, 34 (2020) (suggesting that large-scale deployment of telemedicine will lead to exacerbation of existing health disparities); Lee Schwamm, *Telehealth: Seven Strategies to Successfully Implement Disruptive Technology and Transform Health Care*, 33 HEALTH AFFS. 200, 204 (2014), <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2013.1021> (discussing the major risk of telehealth that low socioeconomic status or other factors might increase health disparities among patients who have limited technology literacy or access).

198. Chunara et al., *supra* note 197, at 37 (finding that Black patients accessed telemedicine more during the pandemic, utilized telemedicine at lower levels when compared to White patients, and may be sicker in comparison when seeking care through telemedicine). *But see* Celeste Campos-Castillo & Denise Anthony, *Racial and Ethnic Differences in Self-Reported Telehealth Use During the COVID-19 Pandemic: A Secondary Analysis of a US Survey of Internet Users from Late March*, 28 J. AM. MED. INFORMATICS ASS'N. 119, 123 (2020) (among internet users, Black respondents were more likely than Whites to report using telehealth because of the pandemic, particularly when perceiving the pandemic as a minor threat to their own health).

199. Chunara et al., *supra* note 198, at 39.

200. Shannon Dowler, Chief Med. Officer, N.C. Medicaid, NC Medicaid Covid-19 Response 11 (June 19, 2020). Telehealth usage did not significantly correlate with the percentage of the population living in rural areas or with the population's broadband access. *Id.* at 12. *See also* Shannon Dowler, Chief Med. Officer, NC Medicaid, Chief Medical Officer (CMO) Update 14 (Sept. 18, 2020) (reporting that teleservice utilization was 1.2 times more likely for urban v. rural, White beneficiaries were 1.2 times more likely to use teleservices than Black beneficiaries, and those with a chronic disease were 2.9 times more likely to use teleservices).

201. David Velasquez & Ateev Mehrotra, *Ensuring the Growth of Telehealth During COVID-19 Does Not Exacerbate Disparities in Care*, HEALTH AFFS. (May 8, 2020), <https://www.healthaffairs.org/doi/10.1377/hblog20200505.591306/full/>.

solving approaches to identify policies that might make safe and effective permanent changes. The following strategies are low risk to participants, improve the direct care workforce stability and generally improve access to providers, expand services, and reduce health disparities:

- Providing individualized, in-home supports and increased home meal delivery to substitute for congregate day programs;
- Permitting qualified providers from other states;
- Allowing family caregivers to become paid caregivers, while still ensuring participant choice of providers;
- Increasing payment rates for direct care workers;
- Expanding access to retainer payments;
- Allowing provision of HCBS in acute care settings;
- Expanding access to medications by waiving prior authorization, permitting cost-sharing, relaxing refill requirements, and allowing exceptions to the preferred drug lists;²⁰² and
- Expanding coverage of telehealth in terms of services, providers, and modalities.

None of these modifications require an emergency. States could readily incorporate them into their standard coverage policies via state policy changes, state plan amendments, or amendments to 1915(c) waivers. States should strongly consider doing so. For example, retainer payments can help HCBS participants retain staff when they have short-term absences from their typical plan of care, such as a brief hospitalization for an illness, even absent a pandemic.²⁰³ The HCBS pandemic changes should inspire new models for services that are more individualized and community-focused, rather than retaining post-pandemic the more traditionally congregate settings, like that of many day programs. Such changes could help HCBS move toward more individually directed and community-focused services, stabilize the direct care workforce, and improve access to prescribed medications.

States should consider the retention of other modifications with caution. States should actively monitor waiver of provider training, staffing ratios, and professional supervision for any adverse consequences during the pandemic. States should take steps now to measure the effect and impact of the HCBS changes, including the equity impacts, in their own states and others to identify effective methods to improve access to HCBS generally.

202. Changes will need to be made on a federal level to eliminate face-to-face requirements for buprenorphine and to allow for longer take-home doses of methadone.

203. *COVID-19 Frequently Asked Questions (FAQs) for State Medicaid and Children's Health Insurance Program (CHIP) Agencies*, CTRS. FOR MEDICARE & MEDICAID SERVS. 60–61, <https://www.medicaid.gov/state-resource-center/Downloads/covid-19-faqs.pdf> (last updated Jan. 6, 2021).

B. Conclusion

The long-term care system in the United States has long favored institutions over community-based programs.²⁰⁴ The COVID-19 pandemic perpetuated this bias in terms of funding, response, data gathering, and attention. Recent pandemic-based efforts to get people out of the hot zones of institutions and into community placements have not been matched with a commensurate push to support the HCBS programs needed by those individuals and their support systems.

States' COVID-19 responses have varied greatly. All took some advantage of available emergency authorities, but these actions supported some HCBS programs and services more than others. All of the changes that states made to their HCBS programs should be evaluated not only for their effectiveness in stabilizing HCBS programs during and potentially after the crisis, but also their effectiveness in reducing race- or disability-based disparities across the populations receiving services and the critical networks of HCBS providers and workers. Importantly, states must investigate who is benefiting, who is not, and whether these changes reduce or, conversely, worsen disparities in HCBS programs.

The COVID-19 changes to HCBS represent an important opportunity to strengthen HCBS programs as both more integrated and more equitable. That can only happen if states and advocates ask the important questions and listen carefully to both the individuals who benefitted from COVID-19-related changes, and to those who did not.

204. *Supra* Section II.A.