



Q&A

Keeping COVID-19 Changes to Home and Community-Based Services

Prepared by
Elizabeth Edwards
National Health Law Program

August 2020

- Q:** Our state is starting to discuss unwinding all of its changes to the Medicaid program due to the COVID-19 pandemic. Many of the changes were to our 1915(c) waivers or otherwise helped HCBS participants. What changes should advocates push to keep?
- A:** Most states made significant changes to their 1915(c) waivers through the use of Appendix K amendments. Some of the more common changes were intended to increase provider availability and access to services. A state is only allowed to do under Appendix K what it could do under a 1915(c) waiver generally. This means that most of these changes could be retained if they were positive for HCBS waiver participants. States are also showing a willingness to retain some of the changes made through other emergency mechanisms that help improve access to HCBS, such as expanding telehealth. The pandemic also revealed other issues, such as lack of data about people with disabilities, which could benefit HCBS advocacy.

Discussion

Many of the changes made to Medicaid home and community-based services (HCBS) under emergency authorities were to add new services, increase existing ones, or relax requirements governing waiver service delivery to provide states with more flexibility. Most of these changes were made to increase the pool of available providers and increase access to services; both of these issues are longstanding problems in most state's waiver programs. Therefore, it would be helpful to retain them. In contrast, however, some of the changes that increased state flexibility may have also lessened the qualifications for providers. Depending on the service and the qualifications in question, advocates should examine these changes more carefully to determine whether they are helpful or harmful. Other changes, such as expansion of telehealth, are typically positive but disability advocates should examine the policies to be sure that

people with disabilities have equal access to them. In addition, the pandemic showed again how inadequate data on people with disabilities is. This creates an opportunity to improve data collection, including examining how HCBS is serving people and whether there are significant differences in how people are supported or their opportunities through HCBS based on other factors. This would be useful in HCBS advocacy in the longer term.

Expanding the Provider Pool

States made a number of changes related to direct care workers. Measures included those to increase the potential pool of direct care workers, as well as those allowing HCBS participants increased options to limit the number of direct care workers they used to limit potential COVID-19 exposure. Some of these changes, such as allowing family caregivers to be paid to provide services, have been used in numerous states for years. Other changes, such as changing provider qualifications or providing retention payments were greater departures from typical HCBS practices. One important common change that would both promote retention of workers and otherwise help people with disabilities was paying for staff in acute care situations. Many of these changes, most of which were made through Appendix K amendments to 1915(c) waivers, may want to be retained as provider shortages are longstanding issues in HCBS.¹

Family as Paid Caregivers

Medicaid typically restricts legally responsible relatives from becoming paid providers of Medicaid HCBS services.² However, states may allow this for most 1915(c) waivers, not all elect to do so.³ To respond to the COVID-19 crisis, about half of the states used

¹ See Elizabeth Edwards, NHeLP, COVID-19 Changes to HCBS Using Appendix K: Approval Trends (Mar. 30, 2020), <https://healthlaw.org/resource/covid-19-changes-to-hcbs-using-appendix-k-approval-trends/>. NHeLP also keeps an ongoing chart with the details of the Appendix K changes. If you have a specific question on Appendix K trends, please send an email to edwards@healthlaw.org. For publicly available charts summarizing changes, see NASHP, States Use Appendix K Waivers to Support Home- and Community-Based Services in Response to COVID-19 (July 13, 2020), <https://www.nashp.org/states-use-appendix-k-waivers-to-support-home-and-community-based-services-in-response-to-covid-19/>; Kaiser Fam. Found., Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19 (July 30, 2020), <https://www.kff.org/medicaid/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/>. For more on the provider shortage issue under COVID-19, see David Machledt & Elizabeth Edwards, NHeLP, Disability, Race, and Structural Inequity: COVID-19 and the Long-Term Care Workforce (Apr. 29, 2020), <https://healthlaw.org/disability-race-and-structural-inequity-covid-19-and-the-long-term-care-workforce/>; Jennifer Lav, Elizabeth Edwards & Daniel Young, Keep Essential Care: Direct Service Professionals, <https://healthlaw.org/keep-essential-care-direct-service-professionals/>.

² Elizabeth Edwards, NHeLP, Q&A Relatives as Paid Providers (Dec. 5, 2014), <https://healthlaw.org/resource/qa-relatives-as-paid-providers/>.

³ *Id.*; see also MaryBeth Musumeci, Molly O'Malley Watts & Priya Chidambaram, Kaiser Fam. Found., Key State Policy Choices About Medicaid Home and Community-Based Services 7, 15, 35, 39 (Feb. 4, 2020), <https://www.kff.org/report-section/key-state-policy-choices-about-medicaid-home-and-community-based->

Appendix K to add or expand the ability to pay family caregivers for at least one 1915(c) waiver program. The allowable services and the parameters under which family may provide paid care vary widely, but this change both expands the provider pool and helps to limit exposure. Allowing paid family caregivers can also increase provider stability. Depending on state rules, particularly nursing rules, sometimes family members can also provide different levels of care, such as some nursing tasks, that non-licensed staff may not be allowed to do.

However, in an HCBS system that compels natural supports, as many do, paying family caregivers may lead to increased burnout of those natural supports. So advocates may want to consider the parameters under which they ask that family caregivers be allowed to be paid caregivers. This of course should always include ensuring participant choice of providers.

Increased Self-Direction

A few states used Appendix K to increase self-direction by lifting restrictions on existing self-directed services, or, more commonly, adding services that were allowed to be self-directed. These services included nursing services, home-delivered meals, and respite. At least one state removed some of the provider qualifications for self-directed care. One of the common additions was for to allow self-direction of home-delivered meal service. In general, expansion of self-direction for services is likely a service change that both will increase access to providers and promote independence for HCBS participants.

Provider Qualifications

A common change in Appendix K amendments has been the removal of certain provider qualifications before a direct care worker begins working with a participant.⁴ These include allowing a worker to start before required background checks were completed or allowing training to occur after starting work. While these changes may have been helpful to provide direct care staff in a time of more frequent turnover, many of the provider qualifications that were waived are important for health and safety.

However, some may have been changes that improved provider onboarding without jeopardizing HCBS participants' health and safety so advocates should closely examine the impact of changes to provider qualifications. Similarly, changes to allow different types of providers to provide more services may require close review to ensure that the changes improve provider availability without diluting the quality of the service. Another common change that may be an easier choice to retain is to allow providers qualified in other states to provide the same or similar services in your state. This is likely especially helpful in areas of the state that border others.

[services-issue-brief/](#) (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).

⁴ Forty-seven states temporarily modified provider requirements. KFF Appendix K Tracker, *supra* note

An important change in many states, which was one of the model recommendations by CMS in the COVID template, allowed HCBS participants to order home delivered meals from a wider variety of providers, including non-traditional providers. Similarly, some states allowed individuals to purchase goods and medical equipment from nontraditional vendors.

Increase in Payment Rates

Over half of the states used Appendix K amendments to allow temporary increases to provider rates. This varied by waiver, service, and conditions under which a higher rate would be paid. One of the most common variations allowed a rate increase up to a certain amount in areas determined by the state to have provider shortages. Gathering information on the effectiveness of any provider rate changes could be valuable in advocacy regarding provider shortages in the future.

Retention Payments

Although long identified as a key part of helping people stay in the community, retention payments have not been common in HCBS waivers.⁵ Under the pandemic, however, almost all of the states have authorized retainer payments in some form or fashion.⁶ Like other changes, the specifics varied by service and payments were time limited, but if made permanent, would help individuals retain staff when they have short-term absence from their typical plan of care, such as a brief hospitalization for an illness.

HCBS Providers in Acute Care Settings

A significant issue during the pandemic was whether individuals with disabilities could be accompanied to acute care settings with any companion, including a provider. Allowing direct care staff to accompany an individual would ensure that their needs were met in a setting already stretched thin and provide familiar support in the very stressful situation. This has been particularly relevant for individuals with needs not easily met by hospital staff, such as specialized communication and behavioral needs.

A majority of states authorized payment for HCBS staff to provide support in acute care settings through Appendix K. However, many of these states limited this to certain services or had strict limitations about when it was allowed. The CARES Act amended 42 U.S.C. §1396(h) by adding two paragraphs, the second of which allowed states to pay for HCBS in acute care settings as long as those services met certain conditions.⁷

⁵ HCFA, Dear State Medicaid Director Letter (July 24, 2000), Att. 3, <https://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/smd072500b.pdf>; CMS, Application for a 1915(c) Home and Community-Based Waiver: Instruction, Technical Guide and Review Criteria 52, 158-60 (Jan. 2019), https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf.

⁶ KFF Appendix K Trackers lists 38 states who include retainer payments to address emergency related issues.

⁷ Congressional Research Service, Selected Health Provisions in Title III of the CARES Act 50-51 (P.L. 116-136), <https://crsreports.congress.gov/product/pdf/R/R46334>. The HCBS must be in the person's plan

While this change does not require states to provide for services in acute settings, it permits it outside of the limited realm of Appendix K amendments. Advocates should gather information about the importance of HCBS in acute care settings to help push for this as an ongoing based part of their waivers.

Using Telehealth to Expand Access

The use of telehealth, both frequency and type of service, expanded rapidly under the pandemic.⁸ States moved quickly to allow for a large variety of services to be offered via telehealth or a hybrid model with some type of home visit or remote monitoring. Some states greatly expanded the types of services telehealth could be used for, especially for HCBS, including adult day, personal care, and services such as physical and occupational therapy. Behavioral health and substance use disorders also saw increased access through telehealth.⁹ States also allowed telehealth for person-centered planning meetings and assessments. Many states are starting to consider what telehealth services to retain after the pandemic ends so they can submit any necessary state plan amendments or other changes. But telehealth has a mix of positives and negatives for people with disabilities.¹⁰

Telehealth Generally

Telehealth appointments can help with many of the barriers to facility based care for people with disabilities including accessibility, transportation, arranging for assistance with transportation and/or appointments, and the time commitment. It can also increase access to care, including specialists, improve patient satisfaction with care, improve clinical outcomes, and result in cost savings.

However, telehealth is largely designed around access to specific technology, including high-speed internet, which is not available to all people, including those with disabilities. This may be because of living in rural areas, limited income to buy devices and high-

of care; provided to meet the needs of the individual that are not met through the provision of hospital services; are not a substitute for services the hospital is obligated to provide; and designed to ensure smooth transitions between acute care settings and HCBS, and to preserve the individual's functional abilities. *Id.* It is not clear that CMS has operationalized this change yet.

⁸ Fabiola Carrion, NHeLP, Top Ten List: Telehealth Coverage During COVID-19, <https://healthlaw.org/resource/top-ten-list-telehealth-coverage-during-covid-19/>; *see also* Fabiola Carrion, NHeLP, Medicaid Principles on Telehealth (May 11, 2020), <https://healthlaw.org/resource/medicaid-principles-on-telehealth/> (outlining a list of principles states should consider when making policy decisions around telehealth); *see also* Kaiser Fam. Found., State Data and Policy Actions to Address Coronavirus, <https://www.kff.org/coronavirus-covid-19/issue-brief/state-data-and-policy-actions-to-address-coronavirus/> (summarizing state actions on telehealth).

⁹ Alexis Robles-Fradet & Abigail Coursolle, NHeLP, Medicaid Offers Critical Support for People Who Are Experiencing Behavioral Health Crises During the COVID-19 Pandemic (May 29, 2020), <https://healthlaw.org/medicaid-offer-critical-support-for-people-who-are-experiencing-behavioral-health-crises-during-the-covid-19-pandemi/>.

¹⁰ Daniel Young & Elizabeth Edwards, NHeLP, Telehealth and Disability: Challenges and Opportunities for Care (May 6, 2020), <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>.

speed internet, inaccessible technology used for telehealth, and low digital literacy. The access to technology influences what type of telehealth will be most useful for different populations and services.

As expected, telehealth usage does typically vary by access to technology. However, recent data also indicates that telehealth usage may vary by the type of service, as well as other factors, including race. For example, in analyzing data on telehealth usage during the pandemic, North Carolina discovered that telehealth usage did not significantly correlate with broadband access or rural areas, but they did find that white beneficiaries had a disproportionately high number of telehealth claims relative to their share of the NC Medicaid population.¹¹

Advocates may want to request data from their state about the use of telehealth, the services used, originating location, and the characteristics of those who used the service. This information should help show whether telehealth is benefiting all that it should and whether there are gaps. Individual reports of telehealth accessibility and usefulness, including whether telehealth worked better for certain services than others and why, would also be helpful information.

Not all services may have truly met a person's needs through telehealth. For example, adult day, personal care, and physical therapy through telehealth may have worked for some, but not all. An important piece of any telehealth policy is that person should always have the choice between telehealth and in-person services.¹² Therefore, a particular telehealth did not have to work for everyone for advocates to suggest keeping it or keeping with some modifications because if it works for some, that may improve access.

Collecting such information and data would be helpful in suggesting policy changes about what telehealth services to keep and how people may access them. Additionally, advocates should remember that broad telehealth policies may not be enough if the populations that need them also have barriers to technology so advocacy on other policies, such as access to assistive technology, may also need to occur.¹³

¹¹ Shannon Dowler, NC DHHS, Presentation at the NC Medicaid Medical Care Advisory Commission: NC Medicaid COVID-19 Response 11-12 (June 19, 2020), <https://files.nc.gov/ncdma/documents/GetInvolved/MCAC/MCAC-NC-Medicaid-COVID-19-Response--19Jun2020-.pdf>.

¹² Carrion, Medicaid Principles on Telehealth, *supra* note 8.

¹³ Daniel Young, Fabiola Carrion & Elizabeth Edwards, NHeLP, Expanding Telehealth Under COVID-19: Supporting Access to Care (Apr. 22, 2020), <https://healthlaw.org/expanding-telehealth-under-covid-19-supporting-access-to-care/>. Six states added assistive technology under their Appendix K waivers and these may be examples to point to regarding changing policies to increase access to telehealth. KFF Appendix K Tracker. In addition, CMS cited the ability of states to authorize devices such as tablets and telephones as a services under § 1915(c)(4)(B) and/or expanding the current definition of as mechanisms to increase access. CMS, COVID-19 Frequently Asked Questions (FAQs) for State Medicaid and Children's Health Insurance Program (CHIP) Agencies, Question III.C.4 (last updated June 30, 2020), <https://www.medicaid.gov/state-resource-center/downloads/covid-19-faqs.pdf>.

Planning & Assessments

During the pandemic, all states moved to some level of remote person centered planning and some states used remote assessments for HCBS. Remote person centered planning may not be preferred by many, but for some HCBS participants it may be optimal. For example, a person may prefer to not travel to a planning facilitator's office but also may not want the whole planning team in their home. Person-centered planning through telehealth could be preferred and this preference of the individual should be the deciding factor.¹⁴ One of the most common changes regarding person centered planning--allowing electronic signatures of plans of care--might be one of the smallest changes that increased convenience and could easily be kept.

Assessments, whether they be for level of care or services, may be a bit more complicated. While remote assessments are feasible in theory, that may depend on what is being assessed, the individual being assessed, the assessment tool, and the technology used.¹⁵ Remote assessments may have communication barriers or miss critical in-person observations. When CMS issued the HCBS Rule, assessments via telehealth were considered and CMS declined to put any limitations on their use.¹⁶

Many of the assessment tools in use through the country rely heavily on demonstrations and observation and the data underlying these tools is based on in-person assessments. It is not clear that the assessment tool and procedures necessarily translate to telehealth, so advocates should really question whether a remote assessment is appropriate for that particular service or program.

Improving Data on People with Disabilities

One of the significant issues that the pandemic has highlighted, yet again, is that data about people with disabilities is often not gathered with any detail.¹⁷ Available data tells us that COVID-19 has disproportionately affected communities of color.¹⁸ In particular, data shows that Black people in this country exposed to COVID-19 have far higher case, hospitalization, and death rates as compared to their white counterparts.¹⁹ And

¹⁴ Person-centered planning is that it must occur at the time and location of convenience of the individual, not the state or other parties 42 C.F.R. § 441.301(c)(1)(iii); 42 C.F.R. § 441.720(a)(3).

¹⁵ David Machledt & Elizabeth Edwards, Home-based Care Under COVID-19: A Do No Harm Approach to Assessing Needs (May 12, 2020), <https://healthlaw.org/home-based-care-under-covid-19-a-do-no-harm-approach-to-assessing-needs/>.

¹⁶ Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2948, 2985-86 (Jan. 16, 2014) (to be codified at 42 C.F.R. pts. 430, 431, 435, 436, 440, 441 & 447, available at <http://www.gpo.gov/fdsys/pkg/FR-2014-01-16/pdf/2014-00487.pdf>).

¹⁷ Daniel Young, NHeLP, Black, Disabled & Uncounted (Aug. 2020), <https://healthlaw.org/black-disabled-and-uncounted/>.

¹⁸ Zamir Brown, NHeLP, Can Coronavirus be the Tipping Point for Health Equity? (Apr. 30, 2020), <https://healthlaw.org/can-coronavirus-covid-19-be-the-tipping-point-for-health-equity/>.

¹⁹ CMS, Preliminary Medicare COVID-19 Data Snapshot (Jan. 1 – June 20, 2020), <https://www.cms.gov/files/document/medicare-covid-19-data-snapshot-fact-sheet.pdf?>; CDC, Health

that there is increased infection risks for members of racial and ethnic minority groups.²⁰ But the COVID-19 data is rarely broken down past number of tests, positive results, hospitalizations, and deaths. Only a handful of states consistently report race data on over ninety-percent of their cases.²¹

Similarly, data also tell us that people with disabilities have been disproportionately impacted by COVID-19. People with disabilities are dying at a higher rate than average.²² In particular, infection and death rates in institutional and other congregate settings are much higher than for the general public.²³ Nursing facilities where Black and Latino residents are at least twenty-five percent of the resident population are two-times as likely to get infected with COVID-19 than nursing facilities with predominantly white resident populations.²⁴

The COVID-19 data tells a lot about the equity issues around COVID-19. But it does so in separate pieces. When COVID-19 data is broken down, it often provides little information about race or disability. It rarely does both, much less provides other information. The failure to stratify COVID-19 data means it is very difficult to identify the impact on people with disabilities beyond that one factor. While we may put together results from data and make assumptions about Black women with disabilities, the data does not tell us the true impact of this pandemic on that population subset. This means that significant information about disparate impact of the pandemic is not being collected, studied, or acted upon.

Localized data has also shown that other factors should be tracked. For example, data

Equity Considerations and Racial and Ethnic Minority Groups (July 24, 2020), https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/race-ethnicity.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fneed-extra-precautions%2Fracial-ethnic-minorities.html; Tiffany Ford et al., Brookings Inst., *Race Gaps in COVID-19 Deaths Are Even Bigger Than They Appear* (June 16, 2020), <https://www.brookings.edu/blog/up-front/2020/06/16/race-gaps-in-covid-19-deaths-are-even-bigger-than-they-appear/>.

²⁰ National Core Indicators, COVID-19 Bulletin #4: Data on Racial Disparities (Aug. 2020) , https://www.nationalcoreindicators.org/upload/core-indicators/Racial_Disparities_in_Time_of_COVID_final.pdf

²¹ The COVID Tracking Project, <https://covidtracking.com/race/dashboard>. Only Arkansas, Delaware, D.C., New Mexico, South Dakota, Vermont, West Virginia, and Wisconsin report race data on over ninety-percent of their cases.

²² Kaiser Fam. Found., *State Data and Policy Actions to Address Coronavirus* (Aug. 5. 2020), <https://www.kff.org/coronavirus-covid-19/issue-brief/state-data-and-policy-actions-to-address-coronavirus/> (showing statistics for at risk populations and those in facilities); Joseph Shapiro, COVID-19 Infections and Deaths Are Higher Among those with Intellectual Disabilities (June 9, 2020), <https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili> (citing rates for NY and PA for people with intellectual disabilities and Autism);

²³ Kaiser Fam. Found., *State Data and Policy Actions to Address Coronavirus*, *supra* note 22 (showing that long-term care facility deaths account for 44% of total state deaths, while on 9% of cases); Jaclyn Jeffrey-Wilensky, COVID-19 May be Deadlier for Group-Home Residents (July 23, 2020), spectrumnews.org/news/covid-19-may-be-deadlier-for-group-home-residents/.

²⁴ Robert Gebeloff et al., The Striking Racial Divide in How COVID-19 Has Hit Nursing Homes, NY TIMES (May 21, 2020), <https://www.nytimes.com/article/coronavirus-nursing-homes-racial-disparity.html>

from New York City shows that Black and Latino populations there are twice as likely to die from the pandemic when compared to the white population.²⁵ Rural regions have also been disproportionately impacted by COVID-19.²⁶ Additionally, many people living in U.S. Territories have more limited access to healthcare and are at higher risk for COVID-19.²⁷ The data that has been collected has also been wildly inconsistent across state, county, and local health systems.²⁸ The piecemeal data without further stratification makes it difficult to fully understand the data and what conclusions may be drawn.

Data collection must improve; to do otherwise will continue to allow the impact of institutionalized biases in health care to be hidden and subsequently ignored. Data collection by the state and other entities on public health issues should include multiple factors and specifically track information about race, disability, sex, limited English proficiency, and other factors where possible.²⁹ The pandemic and the impact of incomplete data is an opportunity to push for this further stratification of data and will help advocates address health equity issues more broadly. For example, better data collection and reporting on HCBS and institutional services will likely reveal differences in who receives what type of service and even differences in service authorizations by different identities. Advocates often can discuss the health equity issues they have identified in HCBS from cases handled, facilities visited, and the like, but showing those inequities is often much harder because the data is not available. Changing the way data is collected could significantly impact advocacy on HCBS.

Conclusion and Recommendations

The pandemic seems likely to continue for some time. Advocates can take this time to consider whether changes made by states to HCBS have been successful and are worthy of pursuing. This may vary by state, HCBS program, or even by service. But the state unwinding process is a significant opportunity to change HCBS programs by keeping what helped HCBS participants.

²⁵ Dr. L.D. Britt, NHeLP (guest writer), The Unveiling and Magnification of Healthcare Disparities in America (July 22, 2020), <https://healthlaw.org/the-unveiling-and-magnification-of-healthcare-disparities-in-america/>.

²⁶ Zamir Brown, NHeLP, Rural North Carolina Remains Vulnerable to COVID-19 Pandemic, <https://healthlaw.org/rural-north-carolina-remains-vulnerable-to-covid-19-pandemic/>.

²⁷ Hector Hernandez-Delgado, NHeLP, COVID-19 Highlights Unequal Treatment of People of Color in U.S. Territories (July 31, 2020), <https://healthlaw.org/covid-19-highlights-unequal-treatment-of-people-of-color-in-u-s-territories/>. The historically underfunded Medicaid block grants to the U.S. Territories, whose residents are largely Black, Indigenous, and People of Color, mean that those individuals have often experienced difficulty accessing services, diminished quality of services, and higher rates of chronic conditions, making them more vulnerable to COVID-19. *Id.*

²⁸ Priscilla Huang, NHeLP, Advancing Health Equity for Asian Americans in the time of COVID-19 (July 21 2020), <https://healthlaw.org/advancing-health-equity-for-asian-americans-in-the-time-of-covid-19/>.

²⁹ *Id.*

