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OFFICE OF BEHAVIORAL HEALTH, DISABILITY, AND AGING POLICY

ISSUE BRIEF

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MEDICAID SECTION 1915(C) HOME AND COMMUNITY-BASED SERVICES WAIVER POLICY FLEXIBILITIES DURING THE COVID-19 PUBLIC HEALTH EMERGENCY: STATE AGENCY, PROVIDER, AND CONSUMER EXPERIENCES

KEY POINTS

- During the COVID-19 public health emergency (PHE), states used Appendix K, a stand-alone appendix available during emergency situations, to temporarily amend their Medicaid Section 1915(c) home and community-based services (HCBS) waivers. States made temporary changes to various aspects of their 1915(c) HCBS waiver programs, including to services, provider payments, and eligibility. We interviewed staff from state agencies and HCBS provider and consumer groups from nine states about their experiences with Appendix K policy flexibilities adopted during the COVID-19 PHE.
- When deciding which Appendix K policy flexibilities to apply for, state agencies primarily considered whether the flexibilities would ensure the health and safety of HCBS users and providers, support provider networks, and address worsening workforce shortages. To inform policy flexibility selection, state agencies relied on their own experiences using Appendix K during prior PHEs or other states' experiences using Appendix K during the COVID-19 PHE, as well as feedback from HCBS provider and consumer groups.
- Challenges with implementing Appendix K flexibilities included uncertainty regarding the duration of flexibilities could be implemented, difficulty accessing and interpreting federal and state agency communication and guidance by HCBS providers and users, limited state administrative infrastructure that did not allow for sufficient data collection and flexibility tracking, and uncertainty and delays with provider payments.
- No state agencies or provider and consumer groups that participated in this study formally evaluated Appendix K policy flexibilities during the PHE; however, at the time interviews were conducted, state agencies were actively discussing evaluation plans.
- All state agencies planned to apply to incorporate at least one Appendix K flexibility they adopted during the COVID-19 PHE into their underlying 1915(c) waiver programs after PHE-related policy flexibilities expired.
- Planning for future emergencies could include developing accessible guidance on Appendix K flexibility selection and implementation; building state infrastructure to support administrative activities (e.g., data collection, tracking of flexibilities) and service delivery via various modalities; and evaluating flexibilities implemented during the COVID-19 PHE using available data.

BACKGROUND

Home and community-based services (HCBS) are a range of medical and non-medical services provided in home and community settings that help people with functional limitations, including older adults and people

with disabilities, reside in their homes and communities, rather than in institutions [1]. For example, HCBS include home health aide, personal care, case management, and habilitation.

The COVID-19 pandemic introduced new challenges to providing HCBS. People receiving HCBS, particularly older adults and people with disabilities, are at greater risk of COVID-19 infection and adverse outcomes, including death, raising concerns about potential COVID-19 exposure associated with HCBS delivery [2]. The COVID-19 pandemic also poses risks for the direct care workforce providing HCBS and has exacerbated workforce shortages [2]. To support Medicaid enrollees' access to HCBS and to support providers during the federal COVID-19 public health emergency (PHE), many states introduced temporary policy flexibilities into their Medicaid programs [3].[a]

States use a variety of Medicaid authorities, including state plan options (e.g., Sections 1915(i) and 1915(k) state plan amendments) and Section 1915(c) and 1115 waivers, to cover HCBS [4]. Of these authorities, 1915(c) wavier programs, which allow states to tailor coverage of HCBS to people who have a level of care need that would otherwise require institutionalization, are both widely used among states and account for a substantial portion of Medicaid HCBS expenditures. In 2020, 47 states, including the District of Columbia, operated at least one 1915(c) waiver program, with the largest share (43%) of Medicaid spending for HCBS going toward 1915(c) waiver programs [5]. In emergency situations, including natural disasters and pandemics, states may amend their 1915(c) waivers using Appendix K to support Medicaid enrollees' access to care [6]. A 2023 issue brief by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) and Mathematica found, during the COVID-19 PHE, states with 1915(c) waiver programs used Appendix K to implement a range of temporary policy flexibilities [7]. Almost all states adopted flexibilities that expanded remote care options or types of providers who could deliver services, modified provider qualifications, increased payment rates, or allowed for retainer payments (see ***Appendix A*** for a table showing the types of flexibilities adopted by states that participated in this study) [7].

In guidance released in 2020, the Centers for Medicare & Medicaid Services (CMS) indicated Appendix K authority (and flexibilities approved under that authority) could remain in effect up to 6 months following the end of the COVID-19 PHE [8]. The COVID-19 PHE expired on May 11, 2023, with Appendix K authority ending on November 11, 2023 [9]. States could choose to let their flexibilities expire earlier, and some states ended certain flexibilities prior to November 11, 2023 [7]. In subsequent guidance, CMS clarified that the expiration deadline for Appendix K flexibilities may be extended if states wanted to incorporate Appendix K modifications into their underlying 1915(c) waiver programs and acted to do so by November 11, 2023 [9].[b] States could apply to amend their waivers to include certain flexibilities, such as virtual service delivery expansions and payment for family caregivers. However, CMS indicated some flexibilities, such as modifications to time frames for level of care evaluations and permitting waiver services to be provided in institutional settings, could not be incorporated into waivers after the PHE [10].

State agencies, HCBS providers, and HCBS users are all affected by the adoption of and expiration (or continuation) of policy flexibilities adopted under Appendix K. Their experiences with Appendix K flexibilities during the COVID-19 PHE could help inform future emergency preparedness, the transition out of the PHE, and future delivery of HCBS. This brief builds upon prior ASPE research investigating the types of Appendix K policy flexibilities adopted by states during the COVID-19 PHE by describing the experiences of select state agency staff and HCBS provider and consumer groups regarding the selection, implementation, evaluation, and

[a] The secretary of the U.S. Department of Health and Human Services determined a PHE existed as of January 27, 2020.

[b] The applicable Appendix K would remain in effect until the effective date of the Section 1915(c) waiver action. For more information, see https://www.medicaid.gov/sites/default/files/2023-08/smd23004.pdf.

integration into underlying Section 1915(c) waivers of Appendix K flexibilities adopted during the COVID-19 PHE.

METHODS

Between January and April 2023, we interviewed state agency staff and staff from HCBS provider and consumer groups in nine states. States were selected to participate in the study based on three main criteria: (1) Medicaid HCBS use during 2020 (the first year of the COVID-19 pandemic) compared to 2019; (2) progress rebalancing Medicaid long-term services and supports (LTSS); and (3) total number of Appendix K categories in which a state adopted policy flexibilities (see ***Appendix B*** for more detail on the selection criteria). When selecting states, we also considered whether the state adopted an Appendix K flexibility categorized as relating to self-direction. After selecting nine states, via email, we invited staff from one or more of the Medicaid, aging, and developmental disabilities agencies in each state to participate in an interview.[c] We identified state contacts through state websites and internal referrals from Mathematica staff. Of the nine states initially selected, agency staff from three states did not respond or declined to participate. We replaced these three states with three alternate states. State agency staff from Connecticut, Louisiana, Maine, Massachusetts, New York, Ohio, Oregon, Washington, and Wyoming participated in this study.

To identify HCBS provider and consumer groups in these states, we asked state agency staff we interviewed for referrals. Although we initially aimed to speak to an equal number of HCBS provider and consumer groups, we determined that provider groups generally had more insight into details of HCBS policy flexibilities than consumer groups and focused our recruitment on the former.

We conducted hour-long group interviews with agency staff from each of the nine states. Interviews included staff from Medicaid agencies in eight states, developmental disabilities agencies in five states, and aging agencies in two states. We also conducted hour-long group interviews with staff from provider groups in seven states and consumer groups in two states. To guide the virtual interviews, conducted via Webex, we used a semi-structured interview protocol covering the selection, implementation, and evaluation of Appendix K policy flexibilities, as well as plans to modify 1915(c) waivers post-PHE. One Mathematica staff person conducted each interview, while another took detailed notes. We extracted findings from state agency interviews and findings from consumer and provider group interviews into separate spreadsheets, organized by four major themes: (1) selection; (2) implementation; (3) evaluation; and (4) continuation of policy flexibilities. We then synthesized and consolidated findings across interviews with state agencies and consumer and provider groups, by theme.

FINDINGS

Selection of Flexibilities

When deciding how to modify their 1915(c) waiver programs through Appendix K, many state agencies we interviewed primarily considered whether a flexibility would ensure the health and safety of providers and Medicaid enrollees. Agencies also prioritized flexibilities based on whether they would support provider financial viability, strengthen provider networks, and address worsening workforce shortages. Ohio tried to select policy flexibilities that could be implemented similarly across the state's HCBS waivers, pursuing a pre-pandemic goal of alignment across waivers.

[c] Because many state Medicaid agencies rely on agencies that provide aging and developmental disability services to administer waivers to specific populations, we reached out to staff from one or more of these agencies in each state to ensure we obtained perspectives from agency staff who administer 1915(c) waivers for various populations.

To inform their decision making, some states relied on insights from prior experiences using Appendix K (either their own experiences from a prior PHE or experiences from other states during the COVID-19 PHE) and feedback from HCBS provider and consumer groups. For example, Louisiana previously made requests to modify 1915(c) waiver programs via Appendix K during weather-related PHEs, and implemented many of the same flexibilities for the COVID-19 PHE. In states where COVID-19 infections peaked later,[d] such as Wyoming and Ohio, staff made decisions informed by the experiences of states with earlier COVID-19 outbreaks, as well as later versions of the Appendix K template, which CMS revised based on states' early experiences. Conversely, states where COVID-19 infection rates peaked early[e] relied on a trial-and-error approach. Agencies in Massachusetts, Connecticut, Washington, Oregon, and New York initially applied for a broad set of Appendix K flexibilities, but did not implement them all immediately and applied for subsequent amendments as their populations' needs became better known over time.

When deciding which Appendix K policy flexibilities to apply for, state agencies considered whether the flexibilities would ensure the health and safety of providers and Medicaid enrollees, support provider networks, and address worsening workforce shortages.

Although states did not conduct formal assessments of consumer and provider needs, citing lack of time and capacity, state agencies also engaged with the public to solicit feedback to inform decisions regarding flexibilities. At the start of the COVID-19 PHE, state agencies (e.g., in Connecticut, Maine, New York, Ohio, Wyoming) implemented weekly, monthly, or quarterly virtual public stakeholder meetings with case managers, providers, and HCBS users and their family members and caregivers. Although stakeholder calls were open to all, many were primarily directed toward, and attended by, provider groups. All provider groups we spoke with participated in calls with state agencies to provide input on Appendix K flexibility selection, but highlighted that selecting flexibilities was largely a state-driven process. Some larger provider groups (e.g., those in Connecticut, New York, Washington, Oregon, Wyoming) advocated for specific flexibilities (e.g., rate increases and other workforce-related flexibilities); smaller provider groups did not mention directly advocating for specific flexibilities.

The nine states participating in this study adopted various types of Appendix K flexibilities (see ***Appendix A***). All participating states applied for flexibilities related to virtual service delivery, including allowing for virtual signatures, virtual and telephonic level of care assessments and reassessments, virtual person-centered care plan development, and expanded use of assistive technology. State agencies considered these flexibilities necessary in the short term to maintain continuity of care and minimize points of contact with individuals outside of the household, in part because of closures of day habilitation facilities and other in-person facilities. HCBS provider and consumer groups echoed the importance of virtual service delivery-related flexibilities. For example, a provider group from New York recommended the state meet people where they were--whether that was by delivering services virtually or allowing reimbursement for care provided out of state or in a family home.

With provider financial viability as another key consideration, all state agency staff we interviewed highlighted the importance of enhancing provider payment, through rate increases, overtime payments, or retainer payments, to maintain staffing levels. For example, state agency and provider group staff in Washington highlighted the importance of retainer payments to support providers who would have otherwise lost income

[d] For information regarding the timeline of the COVID-19 outbreak in the United States, see https://www.cdc.gov/museum/timeline/covid19.html.

[e] Participating states with early outbreaks included those on the East Coast (Connecticut, Massachusetts, New York) and in the Pacific Northwest (Oregon, Washington).

due to decreased service use. Although all provider and consumer groups we spoke with agreed with the need for flexibilities that state agencies adopted, some wished state agencies had done more to extend the duration of rate increases or pay providers more. In Maine, for example, advocates expressed interest in an extended time period for retainer payments, more hazard pay, and temporarily increasing payment rates for more than 2 months at a time.

Appendix K also was viewed as a pathway to implement flexibilities that would help attract and retain quality LTSS staff. Given ongoing workforce shortages, all states and advocacy groups stated the importance of flexibilities for providing virtual care and services, especially in states with large rural populations (Washington, Wyoming). In addition, more than half of state agencies we spoke with (Connecticut, Louisiana, Maine, Ohio, Oregon, Wyoming) allowed payment for services rendered by caregivers or legally responsible individuals, with a majority (Connecticut, Louisiana, Maine, Oregon, Wyoming) citing ongoing workforce shortages as a primary reason for applying for these flexibilities. For example, Wyoming allowed Medicaid enrollees in their Community Choices Waiver who participate in self-direction to hire and pay spouses to provide personal support services. Maine rapidly scaled up infrastructure to expand self-direction.

State agencies described a variety of reasons for choosing not to apply for certain Appendix K flexibilities, including, but not limited to, anticipated difficulty in unwinding them (e.g., New York, Maine), administrative burden for the state (e.g., Ohio), concern regarding economic impacts (e.g., Washington), and having services and populations covered by other HCBS authorities (e.g., Oregon's 1915(k) state plan option). Although Maine was the only state in our sample that implemented an Appendix K flexibility expanding self-direction, others cited existing self-direction programs, lack of infrastructure, and lack of staff or administrative capacity, rather than a lack of interest, as reasons for not expanding self-direction.

Implementation of Flexibilities

State agencies' strategies for implementing Appendix K flexibilities included creating priority rankings of flexibilities and engaging in continuous and iterative stakeholder outreach after adopting flexibilities. Multiple state agencies (Connecticut, Louisiana, Massachusetts, New York, Wyoming) created an order of priority for how they would implement flexibilities approved by CMS. With this strategy, some approved flexibilities were never implemented. For example, Louisiana received approval to allow adult day health care providers to be added as a provider type that can provide personal assistance services under the state's Adult Day Health Care Waiver, but the state's aging agency implemented other flexibilities to support adult day health care providers and did not need to implement these flexibilities.

Uncertainty regarding the duration of Appendix K flexibilities, unclear communication, and limited administrative and virtual service delivery infrastructure presented challenges to implementing flexibilities.

State agencies also engaged in continuous and iterative communication with HCBS provider and consumer groups, as well as HCBS users and their families and caregivers, to implement and modify Appendix K flexibilities. In addition to holding regular meetings, all states communicated informally, by email and phone, and posted information about flexibilities on their websites. At least two states (New York, Washington) conducted special outreach to HCBS consumers using self-directed services. Beyond this specialized communication to people self-directing services, many states relied on case management agencies to provide HCBS users with information about the flexibilities.

State agency staff emphasized that they were often short-staffed and overwhelmed while they were implementing their Appendix K flexibilities, but they did their best with the information they had at the time. Provider and consumer groups echoed this sentiment. Specific implementation challenges included

uncertainty regarding how long Appendix K flexibilities would remain in effect, unclear communication between federal and state agencies' and HCBS providers and consumers, administrative challenges with flexibility approval and tracking, and limitations with virtual service delivery.

Some state agencies (e.g., Connecticut, New York, Ohio, Oregon) expressed that communication with external groups, HCBS providers, and HCBS users about Appendix K flexibilities could have been improved. State agencies struggled to plan around the uncertain duration of the PHE; they wished they had communicated the ambiguity regarding the duration of the flexibilities more directly and consistently. Many HCBS provider and consumer groups corroborated this perspective by highlighting gaps in communication that made implementation a challenge. All provider groups would have preferred earlier and more frequent communication from states. One provider group cited difficulties obtaining direct answers from a state about flexibilities. Relatedly, HCBS consumer groups felt they were not well informed about the flexibilities and had to rely on provider agencies and advocacy groups to communicate policy changes to HCBS recipients. In addition, state agencies faced challenges sharing policy changes with underserved communities, citing difficulty translating information into multiple languages, difficulty communicating information through telephone calls, enrollees' limited access to the Internet and, for those with access, lack of familiarity with the Internet.

HCBS provider and consumer groups also struggled to find and interpret policy changes and administrative guidance used by state and federal agencies. Some providers found out about flexibilities only after they had been in place for a while. One provider group mentioned that the federal documentation for Appendix K flexibilities was difficult to understand, and there was no centralized source that they could refer to for accessible and actionable information. Instead, advocates were often referred to states' Appendix K documents on Medicaid.gov, which do not contain implementation guidance. Another provider group stated that dense programmatic language in state and federal documents made information about Appendix K flexibilities difficult for HCBS providers and consumers to understand, but noted that this issue was present before the COVID-19 PHE, as well. This group suggested that offering providers and HCBS recipients more succinct information, in plain language, would have been beneficial. Similarly, a consumer group relied on provider associations to take dense messaging from the state Medicaid agency and distill it into more understandable messaging for HCBS recipients.

All state agencies also cited a variety of administrative challenges with implementation. One state implied that some Appendix K flexibilities were not adopted because of difficulty getting approval from CMS, which required documentation to back up a request. Some state agencies expressed frustration with the need to submit multiple applications for similar flexibilities under various waivers and difficulty in keeping track of which policy changes applied to services under each waiver. In addition, because Appendix Ks were posted publicly, one state agency unexpectedly needed to field stakeholder questions about flexibilities it applied for as a contingency plan and ultimately did not implement, contributing to administrative burden for the state. To help clarify the process of applying for and implementing Appendix K flexibilities, one provider group suggested CMS hold a stakeholder debriefing to inform the development of an operational toolkit describing flexibilities that could be implemented during future PHEs. Interviewees from both state agencies and provider and consumer groups also expressed streamlined flexibility application processes and guidance on flexibility implementation should be part of any toolkit. For example, the provider group from Ohio mentioned it would be useful to be able to trigger a range of waiver changes at once, instead of having to apply for individual flexibilities.

Upon implementing flexibilities, some state agencies (e.g., Louisiana, Oregon) highlighted difficulties tracking the various changes to their HCBS programs, as their systems were not set up to track policy changes with differing expiration dates and exceptions. For example, Medicaid staff from Louisiana had to rely on time-consuming manual data collection, using an online survey to gather information about the use of flexibilities

from regional office staff performing day-to-day operations. Both state agencies and provider groups spoke about the importance of building administrative and service-related infrastructure (e.g., to track flexibilities) and developing a streamlined emergency plan for implementation.

Provider groups described uncertainty and delays with provider payment, although state agency interviewees did not raise these issues. For example, provider groups from Washington had to obtain reauthorization each quarter for additional funding, with the uncertainty regarding funding extensions making it difficult to plan. The provider group from New York described the length of time it took providers to receive payments as a particular pain point. In Louisiana, a provider group described difficulties securing hazard pay and overtime for staff who were working in 2020; payments were delayed so long that staff left their jobs and were unable to access the hazard pay once their former employers finally received the funds from the state.

Although the expansion of virtual service delivery was often cited as a positive change, interviewees also mentioned implementation challenges. Agency staff in Wyoming and Washington described lack of access to virtual services for many older adults and people with disabilities in rural areas. A provider group from Washington found providing care telephonically to people who do not speak English as a first language challenging. Another provider group from Connecticut highlighted that some providers did not have the infrastructure to provide services via video call. Agency staff from three states (Connecticut, Washington, Wyoming) and three provider groups explicitly highlighted concerns about conducting level of care assessments over the phone, as it is harder to assess deterioration and determine the level of care needed without assessing a person's physical environment.

Evaluation of Flexibilities

No state agencies or HCBS provider or consumer groups interviewed had conducted formal evaluations of Appendix K flexibilities during the COVID-19 PHE. However, all state agencies expressed an interest in formally evaluating flexibilities, although agencies were at different stages of evaluation planning. State agencies discussed a variety of data sources that might be used for evaluations. Some states (e.g., Connecticut, New York, Oregon) cited available data they collected during the PHE that they were examining, or could examine, to inform decisions to incorporate flexibilities into their waiver programs post-PHE. For example, Connecticut created a dashboard, using data from case management entities and other sources, to track certain metrics related to the implementation of flexibilities, such as overtime use, emergency hiring of staff, demand for HCBS, and COVID-19 diagnoses and related hospitalizations. Washington collected operational data on requests for funding limit increases and respite hours. Other state agencies mentioned feedback received from provider and consumer advocacy groups and HCBS users and their families.

No state agencies or advocacy groups interviewed had conducted formal evaluations of the Appendix K flexibilities implemented during the COVID-19 PHE.

Some states (e.g., Maine, Ohio, Oregon, Wyoming) cited standardized quality and workforce surveys (e.g., National Core Indicators-Intellectual and Developmental Disabilities State of the Workforce Survey) as a source of historical data that also might be used to assess the quality of and access to services during the PHE. Provider groups similarly cited data they collected as part of routine surveys (e.g., National Committee for Quality Assurance customer satisfaction surveys and provider surveys), as well as anecdotal data they collected. Consumer groups interviewed did not collect data.

Interviewees shared their informal qualitative assessments of Appendix K policy flexibilities. All states and provider and consumer groups mentioned substantial use of virtual service delivery, virtual case management, and virtual assessments and signatures. All states and provider and consumer groups interviewed cited provider rate increases, overtime payments, expedited hiring, and retainer payments as widely used and

effective. States that allowed payment for services rendered by family caregivers or legally responsible individuals (e.g., Louisiana, Ohio, Wyoming) found that this flexibility was critical for mitigating workforce shortages and maintaining continuity of care, a finding that several provider and consumer groups confirmed. However, some states found that home-delivered meal services (Connecticut, Maine, New York), changes to provider qualifications (e.g., Connecticut), and assistive technology services (Maine, New York) were used less than expected.

Interviewees also described key evaluation topics they would be interested in investigating if data were available. For example, interviewees were interested in the experiences of direct service providers (DSPs) and what flexibilities DSPs found most helpful; the efficacy of enhanced payment rates to create more sufficient provider networks, particularly in areas where provider recruitment is difficult; and how smart home technology, such as alarms and sensors, can help address workforce shortages.

Continuation of Flexibilities Beyond the PHE

Although state agencies emphasized that Appendix K flexibilities addressing the acute emergency (e.g., those relaxing provider certification requirements) were no longer necessary, they described certain flexibilities that they expected to apply to continue in their 1915(c) waiver programs in some capacity (e.g., flexibilities related to virtual service delivery, overtime payments, and self-directed services). All states planned to incorporate virtual service delivery-related policy changes into their waivers post-PHE. Some states (Connecticut, Maine, New York, Wyoming) said the PHE enabled them to test policy changes, such as expanding virtual service delivery, that they had been considering for years, but did not have the infrastructure to implement until now. Five states (Louisiana, Maine, Massachusetts, New York, Washington) planned to incorporate expansions to assistive technology services. Three states (Louisiana, Ohio, Wyoming) expected to add or expand payment for services rendered by caregivers or legally responsible individuals to their waivers. Three states (Connecticut, New York, Ohio) planned to continue payment-related flexibilities (overtime, financial incentives, per diem payments for shared living services). State agency staff from Connecticut and New York noted that they were considering incorporating overtime and other financial incentives into their waivers, in part, to be responsive to the changing costs of service provision. On the other hand, Maine was not planning to incorporate incentive or bonus payments. Maine expected to maintain its expansion of self-direction, using lessons learned to scale up the self-direction program for its HCBS Lifespan waiver,[f] which is under development.

Every state agency interviewed planned to apply to incorporate at least one of the Appendix K flexibilities they implemented during the COVID-19 PHE into their 1915(c) waivers post-PHE.

States were working closely with advocacy groups to gather feedback on incorporating Appendix K flexibilities into waivers moving forward. All provider and consumer groups we spoke with generally supported the flexibilities state agencies planned to request to incorporate post-PHE. For example, advocacy groups supported state agencies' (e.g., Connecticut, Louisiana, Maine, New York, Ohio) plans to continue virtual service delivery flexibilities with modifications to ensure safety and quality of care. Advocacy groups from Ohio supported implementing a cap on the number of virtual service visits allowed. Most states (e.g., Connecticut, Louisiana, New York, Wyoming) planned to limit the use of telephonic assessments and virtual care. Some provider groups (e.g., Connecticut, Louisiana, Ohio) expressed concerns with allowing caregivers or legally responsible individuals to provide services and advocated for limitations on these services. For example, one

[f] The Maine HCBS Lifespan waiver aims to help people with intellectual and developmental disabilities, autism, or both, by addressing their changing needs as they transition through various stages of life. It is currently in development, having gone through two public comment sections in summer 2023. For more information, see https://www.maine.gov/dhhs/oads/about-us/initiatives/hcbs-lifespan-project.

advocacy group noted that monitoring these caregiver flexibilities would be difficult, especially with regards to billing. State agencies echoed these concerns, and planned to modify policy changes related to these services (e.g., Ohio would place a cap on the number of hours for caregivers). Most advocacy groups (e.g., in Louisiana, Maine, New York, Washington, Wyoming) reported that they would have liked to see permanent rate increases or other ways to incentivize staff, but understood that these changes may not be possible for budgetary reasons.

DISCUSSION

Our findings have implications for future emergency planning. The U.S. Department of Health and Human Services, CMS, and states should use their experiences, as well as the experiences of providers and HCBS users and their families and caregivers, with Appendix K flexibilities during the COVID-19 PHE to inform planning and preparation for future PHEs. State agencies and advocacy groups highlighted opportunities to improve the timeliness and clarity of communication and guidance regarding the selection and implementation of Appendix K flexibilities. Interviewees also highlighted an opportunity to create an operational toolkit to support the use of Appendix K during future PHEs. Similarly, a SCAN Foundation report from 2023 recommended developing PHE-related provider or health plan contract clauses and a "playbook" containing flexibilities that can be deployed during various types of emergencies [11].

Given the challenges state agencies faced with monitoring and evaluation, state and advocacy interviewees described the importance of establishing infrastructure for tracking flexibilities and improving data collection for evaluation. In a 2021 report, the U.S. Government Accountability Office found CMS relied largely on states to monitor the impacts of the flexibilities, although CMS intended to evaluate temporary changes made to HCBS programs during the COVID-19 PHE [12]. Enhanced state infrastructure that enables monitoring and data collection would allow state agencies to better conduct these activities during future PHEs.

All states interviewed planned to continue at least one of the temporary HCBS flexibilities implemented during the PHE, in certain cases modifying policy changes for a non-emergency environment. Types of flexibilities state agencies anticipated requesting to add to their waivers included virtual service delivery, assistive technology services, payment for services rendered by a caregiver or legally responsible individual, and various payment-related flexibilities. State responses to surveys by CMS and Kaiser Family Foundation (KFF) were similar. A CMS survey found that states planned to add flexibilities regarding virtual service delivery, paying legally responsible adults, and self-direction to their waivers, among other planned changes to their HCBS programs [13]. Similarly, a KFF survey found that 29 states were planning to continue flexibilities related to virtual service delivery [3].

In addition, states have engaged in a variety of activities under American Rescue Plan Act of 2021 (ARP) Section 9817 using federal and state funding to enhance HCBS [14]. These activities may address certain challenges raised in our interviews, particularly with regard to workforce shortages and virtual service delivery. For example, states are planning on strengthening the workforce by implementing rate increases and retention payments and one-time bonuses [14]. Further, states expect to start or expand virtual service delivery and provide necessary equipment to HCBS users [14]. States should incorporate lessons learned from adoption of Appendix K flexibilities when implementing HCBS enhancements under ARP Section 9817.

Limitations

Our study has several limitations. First, we spoke with state agencies and advocacy groups in only nine states, so our findings may not be generalizable. Second, states use multiple Medicaid authorities (e.g., 1915(c), 1115, 1915(k)) to provide HCBS to qualified individuals. This brief focuses exclusively on temporary modifications to states' 1915(c) waiver programs and does not capture PHE-related modifications states made to HCBS

programs under other authorities. Further, we were unable to speak with Medicaid, aging, and developmental disabilities agencies in all participating states. For New York, Oregon, and Washington, most of our insights came from conversations with staff that work on the states' developmental disabilities waivers; therefore, our findings might be missing key insights related to flexibilities for aging waivers. Finally, we interviewed only two HCBS consumer groups and did not speak to any HCBS users directly. Future research should explore the perspectives of HCBS users and their families and caregivers regarding the temporary changes to HCBS programs that states made during the COVID-19 PHE, as they may differ from those of state agencies and provider groups.

CONCLUSION

The COVID-19 pandemic has had an unprecedented impact on the delivery of HCBS. During the COVID-19 PHE, states used Appendix K to amend their Medicaid Section 1915(c) waivers to make temporary changes to services, provider payments, eligibility, and other aspects of their HCBS programs. State agencies prioritized the health and safety of Medicaid enrollees and providers when selecting and implementing flexibilities. State agencies and HCBS provider and consumer groups encountered various challenges when implementing Appendix K flexibilities. Planning for future PHEs could include developing guidance regarding Appendix K flexibility selection and implementation; building infrastructure to support administrative activities, such as data collection and monitoring and service delivery via various modalities; and evaluating flexibilities implemented during the COVID-19 PHE, using available data.

APPENDIX A: APPROVED APPENDIX K POLICY FLEXIBILITIES

Table A.1. Types of Approved Appendix K Policy Flexibilities, by State (as of June 30, 2023)

Policy Flexibility Category	CT	LA	MA	ME	NY	OH	OR	WA	WY
Access and eligibility[1]	X		X			X			
Increase factor C[2]									
Other changes necessary[3]	X	X	X	X	X	X	X	X	X
Services[4]	X	X	X	X	X	X	X	X	X
Temporarily allow for payment for services for the purpose of supporting waiver participants in an acute care hospital or short-term institutional stay	X		X					X	X
Temporarily include retainer payments to address emergency related issues	X	X	X	X	X		X	X	
Temporarily increase payment rates	X	X	X	X	X	X	X	X	X
Temporarily institute or expand opportunities for self-direction				X					
Temporarily modify incident reporting requirements, medication management, or other participant safeguards	X		X	X	X			X	
Temporarily modify person-centered service plan development process and people responsible for person-centered service plan development, including qualifications	X	X	X	X	X	X	X	X	X
Temporarily modify processes for level of care evaluations or re-evaluations (within regulatory requirements)	X	X	X	X	X	X	X	X	X
Temporarily modify provider qualifications	X	X	X	X	X	X	X	X	X
Temporarily permit payment for services rendered by family caregivers or legally responsible individuals	X	X		X		X			X
Time period extension	X	X	X	X	X	X	X	X	X

NOTES: We gathered information on Appendix K applications by state from the National Academy for State Health Policy's (NASHP) tracker,[5] the Medicaid and CHIP Payment and Access Commission's (MACPAC) webpage on 1915(c) HCBS waiver Appendix K modifications,[6] and Mathematica's analysis of Appendix K documents.[7]

1. Access and eligibility modifications include, but are not limited to, increasing cost limits for entry into the waiver and modifying additional targeting criteria.
2. Factor C is the maximum unduplicated number of participants a waiver program is allowed to serve.
3. Other changes include, but are not limited to, modifications to data collection and reporting requirements.
4. Service modifications include, but are not limited to, virtual service delivery modifications (e.g., allowing electronic service delivery to continue services remotely in home) and exceeding service limitations.
5. NASHP's tracker is available at https://nashp.org/states-use-appendix-k-and-emergency-waivers-to-support-home-and-community-based-services-in-response-to-covid-19/.
6. Information collected by MACPAC is available at https://www.macpac.gov/subtopic/1915c-hcbs-waiver-appendix-k-modifications/.
7. This analysis is available at https://aspe.hhs.gov/sites/default/files/documents/ff458f8d7510982cf6e3062e82e495f8/state-hcbs-policy-flexibilities-during-covid.pdf.

APPENDIX B: STATE SELECTION CRITERIA

Medicaid HCBS use patterns. To assess the changes in Medicaid HCBS use by state during the COVID-19 pandemic, we first determined the pre-pandemic ranges for each state by calculating the average and standard deviation of monthly counts of HCBS users using data from March 2019 to December 2019. We then calculated the averages of monthly counts of HCBS users from March 2020 to December 2020 for each state and compared these values with their respective pre-pandemic ranges. Based on the comparisons, we classified states into three categories: (1) those with usage below the pre-pandemic range (below baseline); (2) those with usage within the pre-pandemic range (within baseline); and (3) those with usage above the pre-pandemic range (above baseline).

Progress rebalancing Medicaid LTSS. We used the measure of state Medicaid HCBS expenditures as a percentage of total Medicaid LTSS expenditures from the Medicaid Long Term Services and Support Annual Expenditures Report (Federal Fiscal Year 2019) [5] to categorize states into quartiles based on the percentage of LTSS spending for HCBS.

Total number of categories in which a state adopted Appendix K policy flexibilities. We identified the total number of categories in which states adopted flexibilities, based on Mathematica's April 2022 analysis of 1915(c) Appendix K flexibilities adopted during the COVID-19 PHE [2,7].

Table B.1. States Interviewed, by LTSS Rebalancing Measure Quartile, HCBS Use Patterns, and Number Appendix K Categories with an Adopted Flexibility

HCBS use patterns during the PHE	Rebalancing Measure Quartile			
	Quartile 1 0.0 ≤ x ≤ 47.5	Quartile 2 47.5 < x ≤ 55.2	Quartile 3 55.2 < x ≤ 63.8	Quartile 4 63.8 < x ≤ 87.4
Above		Wyoming (9) (2)*	Maine (11) (3)*^	Washington (10) (1)*
Within	Louisiana (9) (4)*		Ohio (9) (1)*	Massachusetts (11) (4)*
Below		Connecticut (12) (1)*	New York (9) (2)*	Oregon (8) (1)*

NOTES: The number of categories in which policy flexibility were adopted for each state is in parentheses immediately following each state name. ***Appendix Table A*** lists the number of policy flexibilities by category and state.

The number in parentheses and marked with an Asterix (*) indicates the number of categories in which a state indicates it wants to continue a policy flexibility after the end of the PHE, per KFF Medicaid HCBS Program Survey 2022 (https://www.kff.org/report-section/ongoing-impacts-of-the-pandemic-on-medicaid-home-community-based-services-hcbs-programs-findings-from-a-50-state-survey-appendix/#AppendixTable5).

The caret (^) indicates the state adopted a flexibility categorized as relating to self-direction.

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