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Monitoring and Evaluating Work and Community Engagement Requirements in Medicaid:

Data Assets, Infrastructure and Other Considerations for States

Patricia Boozang, Senior Managing Director
Deborah Bachrach, Partner
April Grady, Director

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Patricia Boozang
Senior Managing Director
Manatt Health
212.790.4523
pboozang@manatt.com

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I. Introduction

Under Section 1115 of the Social Security Act, the Secretary of Health and Human Services (HHS) is permitted to waive certain federal Medicaid requirements to allow a state to undertake an experimental, pilot or demonstration project that is "likely to assist in promoting the objectives of" the Medicaid program. Section 1115 demonstrations are intended to test new approaches in Medicaid and the HHS Centers for Medicare & Medicaid Services (CMS) has long required states to conduct evaluations to determine their effectiveness. CMS also requires states to monitor and submit periodic reports on the implementation of their Section 1115 demonstrations.[1] While monitoring reports provide immediate and ongoing information regarding demonstration implementation, evaluation findings, by contrast, may take years to obtain.

In early 2018, CMS issued guidance signaling its willingness to approve demonstrations that allow states to condition Medicaid eligibility on beneficiaries' meeting work and community engagement (e.g., unpaid work, volunteerism) requirements. Since then, CMS has approved requests to implement work and community engagement (CE) requirements in six expansion states (Arizona, Arkansas, Indiana, Kentucky, Michigan and New Hampshire) and two non-expansion states (Maine[2] and Wisconsin[3]) and is now in the process of reviewing similar demonstration requests from an additional ten states (Exhibit 1). Early demonstration results in Arkansas, the first state to implement such requirements, highlight the high stakes for Medicaid beneficiaries subject to these provisions. Of the approximately 79,000 Arkansas Medicaid enrollees required to engage in work/CE in the first seven months of implementation,[4] over 18,000 lost coverage for failing to meet the new requirements.[5] To date, it is unclear how many of the individuals who lost coverage failed to comply because they had difficulties with reporting, did not work a sufficient number of hours, gained private coverage or had another reason. All states seeking to implement work/CE demonstrations will need to provide sufficient resources for collecting and analyzing data to better understand these issues, and to meet their broader monitoring and evaluation obligations (Box 1).

Even as debate over conditioning health insurance coverage on work/CE requirements continues, one thing is clear: Early and hard evidence about the impacts of these demonstrations is critical, and monitoring and evaluation are crucial sources of this evidence—ultimately allowing states, the federal government and other stakeholders assess whether demonstration goals are being met. **Monitoring reports** provide immediate and ongoing information to help states and CMS both understand how demonstrations are unfolding (e.g., with regard to enrollment and other effects on beneficiaries) and take action to address unintended consequences. **Evaluation reports** answer whether hypotheses about demonstration impacts have been realized or not, and evidence regarding a demonstration's outcomes may take years to obtain. The importance of both monitoring and evaluation cannot be overstated for work/CE demonstrations, which are untested in Medicaid. Because these demonstrations condition eligibility on beneficiaries complying with new administrative processes and engaging in work/CE activities consistent with state standards, and can result in substantial coverage losses, it is crucial to understand how these policies impact beneficiary coverage and whether they achieve intended goals with respect to health and financial independence.

CMS will soon issue detailed federal guidance that lays out "rules of the road" for monitoring and evaluation of 1115 demonstrations that include work/CE requirements as a condition of Medicaid eligibility (Box 1). In this resource guide we examine the data assets and infrastructure necessary to support states and their researcher partners in robust monitoring and evaluation efforts. Further, we discuss the ways in which monitoring and evaluation for work/CE demonstrations should differ from traditional approaches, drawing on discussions with state officials and researchers who are considering options for work/CE demonstration implementation and oversight. Additional background and detail on demonstration evaluation and monitoring requirements are provided in the Appendix.

Box 1. New Rigor Demanded of States for Demonstration Monitoring and Evaluation

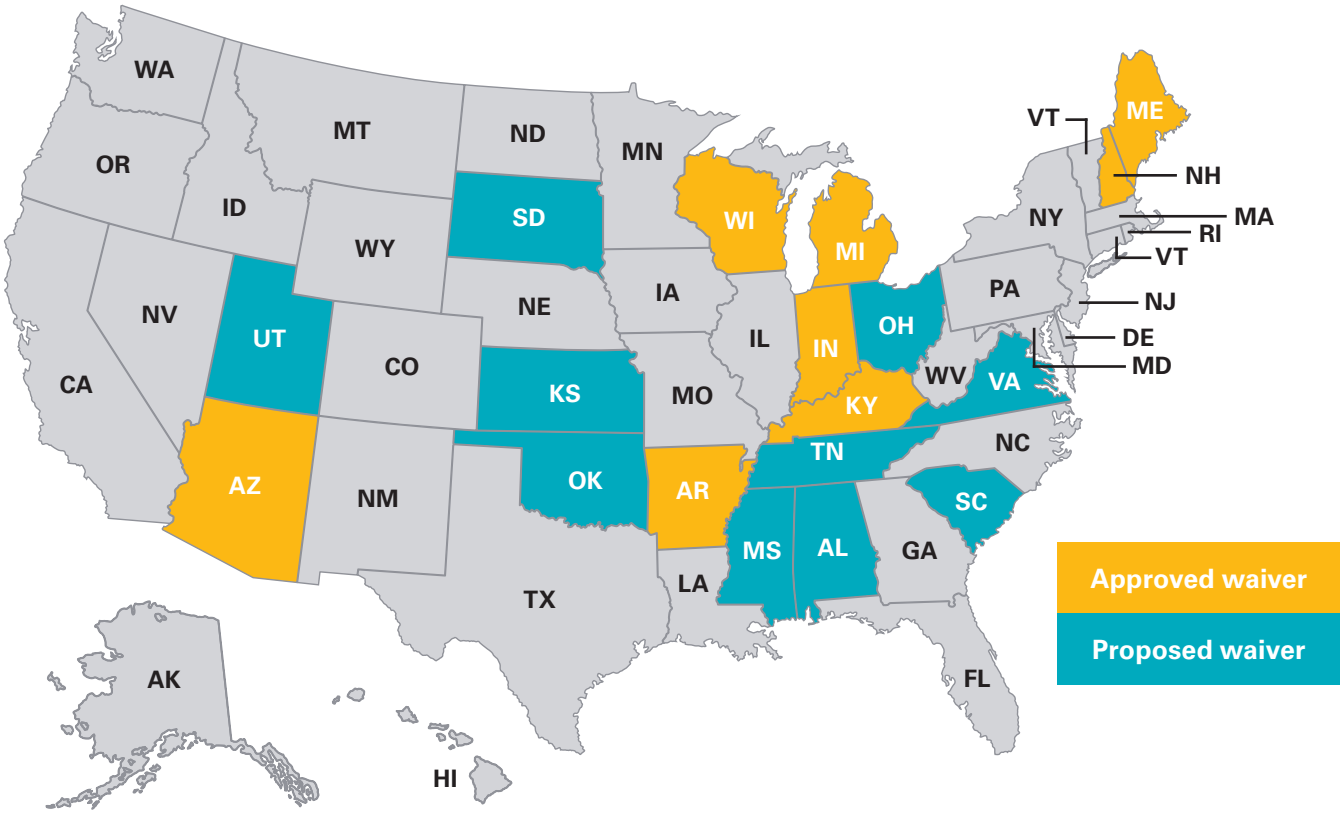
As states have expanded their use of demonstrations, the Government Accountability Office (GAO), members of the research community and others have raised concerns about the adequacy of monitoring and evaluation approaches.[6,7,8] Over the past few years, CMS has sought to inject more rigor into demonstration monitoring and evaluations,[9] including by:

- Developing technical assistance guides for states on appropriate research methods for their evaluations,[10] and increasing feedback to states on strategies to strengthen their evaluation designs and reports.[11]
- Issuing detailed guidance on substance use disorder (SUD) demonstration monitoring and evaluation,[12] including demonstration monitoring protocol and report templates, metrics to be included in the reports and a technical assistance document on developing a SUD demonstration evaluation design.

CMS is in the process of developing and is expected to soon issue similarly detailed guidance for work/CE and other high-priority demonstration types. In anticipation of and in response to this guidance, states will need to consider the resources required for augmenting their monitoring data, as well as designing and executing their work/CE demonstration evaluations.

In general, states and the federal government each shoulder 50 percent of the costs associated with the procurement of an independent evaluator and any new data collection that may be required. In Kentucky, the state is slated to undertake a "gold standard" approach to its demonstration evaluation that involves random assignment of some beneficiaries to participate in the work/CE requirement while others continue their coverage under existing rules,[13] at a cost of $9.4 million through state fiscal year (SFY) 2020—a figure that likely will rise given that demonstration evaluations typically unfold over several years.[14] Arkansas has not yet finalized its work/CE demonstration evaluation plan[15] and is still in the process of procuring a vendor to conduct the evaluation.

Exhibit 1. Approved and Proposed Medicaid Demonstrations With Work/CE Requirements as of February 2019



II. State Data Assets and Infrastructure for Work/CE Demonstration Monitoring and Evaluation

In this section, we identify areas of measurement as well as provide specific examples of the data assets and infrastructure states will find necessary for work/CE monitoring and evaluation. We begin by summarizing the key areas for monitoring, measuring and evaluating work/CE requirement impacts, consistent with evolving CMS requirements (see Appendix), and detail data elements required to inform these measurement areas. Importantly, there is a need to consider demonstration impacts and outcomes for both current and former beneficiaries subject to these requirements—an issue that significantly influences both the scope of measurement and the data assets needed to inform monitoring and evaluation, ultimately answering key questions about the impact of work/CE demonstrations.

While not specifically called out in each section, may of the measures below will benefit from stratification to better understand subgroups that may be disproportionately affected. This could include, for example, stratification by: age and other demographics; area of residence; family composition; income level; education level; primary language spoken; eligibility group before/after being affected by work/CE requirements (e.g., transitions from/to a pregnancy-related or disabled group not affected by the requirements); prior Medicaid service use; health characteristics (e.g., SUD or other diagnoses of interest); and other program participation (e.g., Supplemental Nutrition Assistance Program (SNAP), Temporary Assistance for Needy Families (TANF), unemployment benefits).

Measuring Demonstration Impact on Medicaid Coverage

A critical aspect of demonstration monitoring and evaluation is measuring impacts on Medicaid coverage for subgroups of populations subject to the new requirements, as well as understanding reasons for disproportionate impacts across subgroups.

Affected beneficiary groups

- Number in eligibility group(s) affected by work/CE requirements
- Stratification to better understand subgroup impacts

Actions of individuals in affected groups

- Number of beneficiaries with:
  - No action required, due to exemption or compliance determined administratively, with a breakout of those in various categories
  - Action required to report work/CE activity or exemption
- Among those with action required, the number of beneficiaries:
  - Making contact to report an exemption or work/CE activities, with a breakout of those in various categories and contact types (e.g., online, phone)
  - Not making any contact with state

Consequences

- Number of beneficiaries that were disenrolled or had eligibility suspended that:
  - Did not make contact with state
  - Made contact with state but did not meet work/CE requirements, with disenrollment or suspension on that basis
  - Made contact with state but other factors led to disenrollment or suspension (e.g., increase in income or other change in circumstance)
- Number seeking reinstatement, how many are granted, what the timing is and under what circumstances (e.g., good cause exemption determined retroactively), and who is granting (e.g., eligibility worker versus an appeals entity)

Measuring Demonstration Impact on Work/CE Activities and Related Outcomes

States seeking work/CE demonstration authority hypothesize that making working/CE a condition of Medicaid eligibility will incentivize beneficiaries to find jobs, engage in education, take unpaid work or volunteer in their communities. Measuring the impact of these demonstrations on such activities, and their related outcomes—like income changes and access to private or employer-sponsored health insurance—is therefore central to demonstration monitoring and evaluation.

Employment

- Number employed
- Employment characteristics (availability may be limited depending on the data source)
  - Occupation/industry
  - Duration/seasonality
  - Number of hours worked
  - Number of jobs worked
  - Hourly wage
  - Whether employer-sponsored insurance is offered, and under what circumstances (e.g., waiting period, premium contribution)

Community Engagement

- Number of individuals with activities other than employment (requires active reporting by current enrollees; to obtain this information for people who are disenrolled, states will need to conduct follow-up surveys)
- CE characteristics
  - Community service
  - School attendance
  - Training programs
  - Job search activities
  - Other (e.g., SUD treatment)

Supports

- Number of individuals referred for work supports offered by state, by type
- Number of individuals using support services, by type
- Whether the state is using Medicaid, other programs with a federal funding component (e.g., TANF) or state-only dollars for work supports

Income

- Number of individuals with an increase in income below a level that would affect their Medicaid eligibility

- Number of individuals with an increase in income affecting eligibility for Medicaid or other programs

Insurance coverage other than Medicaid

- Number of individuals gaining other coverage or becoming uninsured (some sources may be available for data matching; follow-up surveys will also be necessary)

Measuring Demonstration Impact on Health

CMS guidance requires that work/CE demonstrations test the hypothesis that work activities and community engagement will improve the health and well-being of individuals subject to these requirements,[16] making it essential that states include in their monitoring and evaluation plans measurement of demonstration impacts on health, both for beneficiaries who remain enrolled in Medicaid and those who are disenrolled.

Healthcare spending and financing

- Medicaid spending characteristics of those who are exempt from, compliant with or non-compliant with work/CE requirements
- Whether individuals are transitioning to other eligibility groups not affected by work/CE requirements (e.g., by seeking disability determination) and implications for federal matching to state
- Changes in uncompensated care for hospitals and other providers

Healthcare service use and diagnoses

- Medicaid service use and diagnoses of those who are exempt from, compliant with or non-compliant with work/CE requirements, as well as non-Medicaid service use for those who are disenrolled
- Changes in insured versus uninsured service use among healthcare providers (some existing sources may be available—for example, emergency department databases compiled by states, but new information collection may also be required)

Measuring Demonstration Impact on Administrative Processes and Costs

Staffing

- State
- County
- Managed care plan

Other administrative issues

- Information technology system investments
- Call center volume
- Mailings and communications
- Referral to and coordination with work supports
- Contract for independent evaluation of demonstration

Data Sources for Work/CE Demonstration Monitoring and Evaluation

Following are data sources on which states can rely to measure the demonstration impacts discussed above. Some of this information will be available from data in existing state Medicaid administrative systems and can be reported with relative ease. Other data sources must be newly generated or will exist outside of the state Medicaid agency and necessitate new data sharing arrangements to enable access, as well as analytic capacity to make use of them. In all cases, financial and other resource investments will be required (Box 1).

States may find it especially challenging to obtain data for individuals who are disenrolled from Medicaid, and must take action on multiple fronts to do so. First, states will want to conduct surveys of former beneficiaries.

Box 2. Data Privacy and Access Issues in Medicaid Demonstration Monitoring and Evaluation

States must comply with federal and state privacy laws in analyzing the impact of Medicaid work/CE requirements.

State Medicaid programs must follow both the privacy rule of the Health Insurance Portability and Accountability Act (HIPAA)[17] and federal Medicaid confidentiality law[18] in reviewing Medicaid data—such as claims and eligibility records—as part of an analysis of the impact of work/CE requirements. Both laws permit the use and disclosure of Medicaid data without written consent from beneficiaries for purposes of program evaluation. HIPAA permits covered entities such as state Medicaid programs to use their own data for purposes of "health care operations," which includes outcomes evaluation. In short, these federal laws permit[19] and CMS has approved[20] the use of Medicaid data for purposes of evaluating Medicaid initiatives.

However, state Medicaid programs may face barriers in their efforts to obtain non-Medicaid data from other sources under **state** privacy laws. For example, state law privacy protections for all-payer claims databases (APCDs) vary. Some states permit the disclosure of identifiable data held by APCDs in certain circumstances (e.g., Arkansas has considered using its APCD for Medicaid demonstration evaluation purposes but has faced data—rather than legal—limitations[21,21]), while other states may prohibit the disclosure of identifiable data or limit the types of entities that can receive such data.[23] In addition, state laws typically restrict the disclosure of information on employment status, unemployment compensation, workforce participation and job training; in some cases, there may be no exceptions to those laws that would apply to the evaluation of Medicaid work/CE requirements. Obtaining information on other benefits may also be difficult. While federal law[24] does allow for disclosures of TANF and SNAP information for purposes of evaluating a federal or state assistance program—including Medicaid—state laws may be stricter.

Moreover, states seeking to understand the health status of former Medicaid beneficiaries and the nature of healthcare services delivered to those beneficiaries may find that the data they receive is incomplete due to privacy restrictions. For example, substance use disorder records covered by 42

Box 2. Data Privacy and Access Issues in Medicaid Demonstration Monitoring and Evaluation (continued)

C.F.R. Part 2 may be removed from records in APCDs or other health information databases due to restrictions on disclosure of such data.[25] Likewise, state privacy laws may limit disclosures of certain types of health information, such as mental health or HIV records.

Finally, there will be other, administrative hurdles in accessing non-Medicaid federal and state data sources that are essential for Medicaid work/CE monitoring or evaluation purposes. For example, a state may wish to examine whether individuals leaving the Medicaid program under a work/CE requirement gain subsidized or unsubsidized Marketplace coverage; however, CMS may need to perform a data match for this purpose and may face resource constraints in its ability to do so (e.g., if a state wanted to monitor this issue on an ongoing basis).[26] Similarly, Medicaid agencies seeking to obtain non-Medicaid data from other state agencies, like tax or labor departments, may confront challenges related to executing data use agreements and effectuating data sharing. However, a recent joint report from Montana's Department of Revenue and its Department of Labor & Industry demonstrates that when these hurdles are overcome, states can harness information from multiple sources that are of high value for monitoring and evaluation of work/CE demonstrations—in Montana's case, painting a rich picture of employment among Medicaid beneficiaries,[27] which could potentially be extended to include those who leave the program.

Additionally, they can explore the possibility of gathering information on disenrollees from administrative sources that are typically available for those who remain in the program (e.g., State Wage Information Collection Agency (SWICA) and other employment-related databases used to verify income eligibility, third-party liability files used to determine whether beneficiaries have other sources of coverage), but privacy and other legal considerations may pose barriers that will need to be addressed (Box 2).

- Data maintained in Medicaid administrative systems:
  - Eligibility records
  - Claims
  - Appeals and grievances
  - Call center records
  - Returned notices and mail
  - Administrative staffing and spending
- Data maintained in other agency administrative systems (for current and former beneficiaries):
  - Supplemental Nutrition Assistance Program (SNAP)
  - Temporary Assistance for Needy Families (TANF)
  - Unemployment compensation (UC)

- State workforce and job training programs
- State Wage Information Collection Agency (SWICA)
- National Directory of New Hires (NDNH)
- Proprietary or state-maintained data on third-party liability (TPL) coverage (e.g., private insurance)
- Proprietary databases with employment/income information (e.g., Work Number, Verify Advantage/ Verify Direct)
- Federal Data Hub (includes information from both government and proprietary databases)
- Marketplace enrollment (for former beneficiaries)
- All-payer claims database (APCD), if maintained by the state (for former beneficiaries)

- Other information from non-administrative sources (for current and former beneficiaries):
  - Beneficiary surveys
  - Beneficiary focus groups
  - Former beneficiary surveys
  - Former beneficiary focus groups
  - Interviews with providers, plans and other key stakeholders

III. Additional Considerations for States

Qualitative data and quantitative data, including for people who are disenrolled from Medicaid as a result of work/CE requirements, should be used in both monitoring and evaluation.

In order for states to understand what is occurring under their demonstrations and why, states will need to review both qualitative and quantitative data, including for people who are disenrolled from Medicaid as a result of work/CE requirements.

Administrative data can be used to quantify changes in Medicaid enrollment; it can also be used to identify the characteristics of those who have lost coverage following the implementation of work/CE requirements. In some cases, states will be generating new administrative data in the course of implementing their work/CE demonstrations, which can be harnessed to inform monitoring and evaluation. For instance, states will begin collecting new information related to the work/CE exemption determinations and compliance with work/CE activities. Appeals and grievances data may be augmented with new information as individuals affected by work/CE requirements seek exemptions or compliance redeterminations. Documentation of outreach to and contacts initiated by beneficiaries (e.g., via the state Medicaid agency and its call center) is another important source of information. Such contacts can be tracked quantitatively, but also examined qualitatively for a better understanding of the challenges that beneficiaries may be facing.

But administrative data will only take states so far. Surveys, focus groups and other interviews will be required in order to obtain additional quantitative data (e.g., on the share of individuals who gain other

coverage or become uninsured after losing Medicaid) and qualitative information (e.g., on beneficiary experiences with work/CE participation and reporting). Given the high stakes for beneficiaries and the fact that administrative data faces a lack of sufficiency for work/CE monitoring purposes, states will want to implement surveys and other supplemental data collection methods from the earliest stages of work/CE demonstration development, implementation and monitoring—rather than incorporating this information in their evaluations alone.

Monitoring from day one of demonstration implementation is essential, and states should consider including in their monitoring plans explicit mechanisms for course correction.

In general, states project that Medicaid enrollment will decline under work/CE demonstrations, with a hypothesis that at least some individuals will transition to employer or other coverage. As noted in the Appendix, recent CMS approvals of work/CE demonstrations require states to submit an implementation plan with a timeline for meeting milestones associated with work/CE policy implementation, as well as a monitoring protocol with metrics that demonstrate state progress toward meeting implementation milestones. It is currently unclear how milestones will be defined for work/CE demonstrations. A basic, but compelling, milestone is maintenance of health coverage for those affected by work/CE requirements—whether through Medicaid or other sources of coverage.

Although quantifying transitions from Medicaid to private coverage will necessitate additional data collection, particularly if a state does not have an APCD, states will be able to measure Medicaid enrollment changes as part of their monitoring plans. In advance of demonstration implementation, states should consider developing "triggers" for course correction based on monitoring or evaluation data. For example, if substantial numbers of beneficiaries are losing Medicaid coverage for failure to report their work/CE hours or if monitoring data suggests that many beneficiaries do not know about or understand the new requirements, these results could trigger action like altering hours requirements, suspending coverage terminations or ending the demonstration altogether.

Notably, in recently approved demonstration special terms and conditions (STCs), CMS reserves the right to require state corrective action plans or to withdraw authority for the demonstration if the agency determines, based on monitoring or evaluation data, that the demonstration would no longer be in the beneficiaries' interest or promote the objectives of Medicaid.[28] This further validates the need for states to establish internal "triggers" that necessitate action.

Box 3. 1115 Demonstration Enrollment Projections as Monitoring/Evaluation Benchmarks

Enrollment projections that are required in state demonstration applications take on heightened importance where continued Medicaid enrollment is core to what is being tested in a demonstration. Although enrollment and other projections developed as part of the demonstration application process are not binding on states, they do provide a critical benchmark against which the results of demonstration monitoring and evaluation activities can be compared.

Box 3. 1115 Demonstration Enrollment Projections as Monitoring/Evaluation Benchmarks (continued)

States that have submitted work/CE demonstration applications to date have been inconsistent in whether and how they calculate projected enrollment effects, making such benchmarking at least difficult and in some cases impossible. For example, the Arkansas 1115 demonstration amendment application did not include enrollment projections, and the state's experience to date suggests large coverage impacts. While Arkansas has made some adjustments to its program administration, changes in response to monitoring results may have been more rapid and extensive had the state articulated anticipated enrollment impacts from the outset.

While Kentucky projects that average monthly expansion adult enrollment will drop by 15 percent under its demonstration,[29] this estimate includes other conditions on eligibility in addition to work/CE (e.g., related to premiums, timely reporting and elimination of retroactive coverage). Separate assumptions related to enrollment impact for each of these conditions are necessary to facilitate benchmarking for monitoring and evaluation purposes.

Among other states with approved work/CE demonstrations, for example, Indiana projects that expansion adult coverage will fall by 4 percent as a result of its work/CE requirement,[30] Wisconsin projects a 3 percent reduction among its affected adult group[31] and New Hampshire expects that enrollment will not change materially under its demonstration.[32] States will want to develop (and CMS should require, consistent with regulation[33]) specific enrollment projections as part of their demonstration applications as foundational to demonstration monitoring and evaluation activities. Such projections may need to be revisited and revised as new evidence becomes available, as Michigan suggests in its recent correspondence with CMS on implementation of the state's work/CE demonstration.[34]

Monitoring and evaluation findings should be shared promptly with the public, other states and stakeholders.

In a MACPAC review of Section 1115 demonstration reports posted online by CMS and by states as of August 2017, most states had quarterly or annual monitoring reports (36 of 43 approved demonstrations); however, only about half had evaluation design plans (26 of 43 approved demonstrations) and about half of those with renewed demonstrations had evaluation findings (13 of 26 renewed demonstrations).[35] In the case of Arkansas's work/CE demonstration, the state has released monthly data[36] and CMS has posted monitoring and evaluation materials (e.g., quarterly reports and an amended draft of the state's evaluation plan[37]) in a timely manner. A driving purpose of Section 1115 authority is to promote the objectives of the Medicaid program through new approaches. Given that numerous states are seeking to test similar hypotheses with regard to work/CE requirements and other policies, greater transparency and sharing of information on these demonstrations are critical. In particular, the ability for states to learn from each other and to receive meaningful public input on demonstration progress can be improved through consistent and timely online posting of monitoring and evaluation materials—including but not limited to reports that must be submitted to CMS.

IV. Conclusion

Work and community engagement demonstrations are premised on the concept that requiring certain Medicaid beneficiaries to participate in paid or unpaid job, education or community activities as a condition of keeping their Medicaid coverage will lead to their sustained employment, support transitions to employer-sponsored or other health insurance coverage, and ultimately improve their health and well-being. While the debate continues, including in the courts, as to whether these demonstrations promote the objectives of the Medicaid program, demonstration monitoring and evaluation are both critical and challenging. States and their researchers are faced with difficult questions about how best to collect, analyze and report data and other information on demonstration impacts—including for people who remain enrolled in the program and those who are disenrolled related to new demonstration requirements. Because work/CE demonstrations are untested in Medicaid, and people face loss of health coverage as a result of the new conditions, the stakes for robust and meaningful monitoring and evaluation are high. States and their researchers will need to take new approaches to using existing and accessing new data sources to support demonstration monitoring and evaluation, departing from traditional data-gathering models and committing to take action if demonstration impacts depart from expected outcomes.

Appendix

Background on Medicaid Section 1115 Demonstration Monitoring and Evaluation Requirements

Section 1115 of the Social Security Act gives the Secretary of HHS the authority to waive Medicaid rules and requirements to enable states to test approaches to providing Medicaid coverage and services that are not otherwise permitted by law, as long as the Secretary determines the proposal will further the objectives of the Medicaid program. Because 1115 waivers are by definition demonstration or pilot programs, CMS requires states to monitor their effects on enrollees and to evaluate whether they advance the stated goals of the initiative.

As part of the 1115 demonstration approval process, federal regulations require states to provide a statement of demonstration hypotheses or expected outcomes of the demonstration; federal regulations further require states to project the expected impact of the demonstration on Medicaid enrollment and CMS to assess whether states have included estimated enrollment impacts before a demonstration application is deemed "complete" and the federal review and approval process can begin.[38] The hypotheses as to the outcome of the demonstration (in this case adding a work/CE requirement to Medicaid) together with the predicted impact on Medicaid enrollment provide the framework for state monitoring and evaluation plans.[39]

Monitoring and Evaluating Work/CE Demonstrations

In 2018, for the first time, CMS began to approve state demonstrations that condition Medicaid eligibility on work/CE and other "personal responsibility" requirements. To date, CMS has approved requests to implement work/CE requirements in eight states (Arizona, Arkansas, Indiana, Kentucky, Maine, Michigan,

New Hampshire and Wisconsin), and ten other states have applied for such demonstrations (Exhibit 1). Monitoring and evaluation of these demonstrations take on new significance given their potential Medicaid coverage implications for otherwise eligible people who are subject to these requirements.

In January 2018, CMS issued a State Medicaid Director Letter (SMDL) that articulates specific monitoring and evaluation requirements as part of overall guidance for states seeking work/CE demonstrations. Among other things, the SMDL sets forth the hypotheses CMS expects states to test: namely, that work/CE requirements will lead to improved health, well-being and (if the state pursues this goal) independence. The guidance also indicates that states are expected to include in their evaluations an analysis of how work/CE requirements affect the ability of Medicaid beneficiaries to obtain sustainable employment, the extent to which individuals who transition from Medicaid obtain employer-sponsored or other health insurance coverage, and how such transitions affect health and well-being. Finally, the guidance indicates that states must examine monitoring metrics that are specific to work/CE requirements, as well as more general metrics aimed at monitoring disenrollment for failure to meet program requirements, access to healthcare services for enrollees and for individuals who are terminated, and the overall functioning of the demonstration.[40]

Immediately following this guidance, CMS issued its first wave of demonstration approvals, for Kentucky, Arkansas and Indiana, followed by approvals later in 2018 and early 2019 for additional states. The STCs for work/CE demonstrations approved in late 2018 and early 2019 reflect more stringent monitoring and evaluation requirements than the earlier CMS approvals, including:

- Hypotheses regarding work/CE requirements that include effects on Medicaid enrollment and continuity of enrollment;
- A monitoring protocol that describes the quantitative and qualitative elements to be included as part of the state's quarterly and annual monitoring reports; and,
- An implementation plan with timelines for meeting milestones for work/CE and other key policies in the demonstration.[41,42]

The STCs for these state demonstrations also indicate that CMS will supply the states with a set of required metrics (and associated technical specifications for data) that demonstrate how the state is progressing toward meeting identified milestones with regard to enrollment, disenrollment and suspension of coverage by specific beneficiary demographics and reason; beneficiary participation in community engagement qualifying activities; access to care; and health outcomes.[43,44]

Notably, the STCs for Arkansas, the first state to implement work/CE requirements, do not include these more stringent provisions. The state has an approved monitoring plan,[45] but the metrics fall well short of monitoring requirements in more recent demonstration STCs; the state does not have an approved evaluation plan for its demonstration as of this writing (now ten months after its demonstration approval). In short, development and implementation of robust monitoring and evaluation requirements for work/CE demonstrations have lagged behind the implementation of the demonstrations themselves, making the additional CMS requirements and forthcoming guidance on work/CE monitoring and evaluation all the more important.

Box 4. Early Monitoring Results in Arkansas

Arkansas is the first state to implement a Medicaid work/CE demonstration program, as of June 2018. Since launching the program, the state's monitoring results reveal that among the first group of expansion adult enrollees age 30-49 subject to work/CE requirements, 23 percent overall were disenrolled for non-compliance; among the subgroup who were non-exempt and required to report work/CE activities, 75 percent were disenrolled.[46] More than 18,000 expansion adults were disenrolled through the end of December.[47]

Several months after implementation, little information is available on the reasons why large numbers of enrollees have not met the state's requirements for work/CE participation and reporting,[48] some of whom may remain unaware of the requirements despite outreach efforts.[49] CMS has indicated that it is still trying to understand why people failed to meet the requirements (and as a consequence were terminated from the program),[50] and the state recently expanded its previously online-only reporting system to include a phone option.[51] Among other issues, beneficiary focus groups conducted in Arkansas during November 2018 revealed ongoing confusion about the new work/CE participation and reporting requirements, difficulties navigating the online system and barriers to work driven by a variety of labor market and personal circumstances.[52]

CMS is in the process of developing the standardized metrics for work/CE demonstration monitoring, and has convened a technical advisory group comprising states and researchers to provide input into its evolving metrics set. CMS is also drafting evaluation guidance for states with work/CE demonstrations that will articulate required hypotheses and evaluation questions, address the incorporation of comparison groups in order to understand the impact of the demonstration on the population of interest, and give guidance on tracking beneficiaries longitudinally, particularly after they leave Medicaid, in order to fully capture the impacts of the demonstrations.[53] CMS's new guidance and metric requirements for work/CE demonstrations is expected to be akin to the toolkit that CMS has provided to states related to monitoring and evaluation of waivers of statutory IMD limits for SUD and serious mental illness/serious emotional disturbance[54,55] and will provide a crucial source of direction for states that are seeking to implement work/CE requirements. CMS's new monitoring and evaluation guidance is expected to be released in early 2019.

In the coming months, additional states will implement work/CE demonstrations, with expanded monitoring and evaluation guidance from CMS—creating a base of evidence as to their actual experience against expected impacts. As implementation moves forward and additional states consider seeking work/CE demonstrations, rigorous monitoring and evaluation are essential. As indicated in this resource guide, attention to data assets and infrastructure is required to support states and their researcher partners in monitoring and evaluating 1115 demonstrations that impose work/CE requirements. Monitoring and evaluation of these demonstrations should differ from traditional approaches in a variety of ways given the high stakes for Medicaid beneficiaries: namely, loss of health insurance.

[1] The Affordable Care Act formalized some of these long-standing practices by requiring the Secretary of HHS to promulgate regulations regarding public notice and comment, periodic implementation reporting, periodic evaluation and certain other requirements of Section 1115 demonstrations; see Social Security Act § 1115(d) and 42 C.F.R. § 431, Subpart G.

[2] In a January letter to CMS, Maine declined to accept the waiver terms. Janet T. Mills to Seema Verma, "MaineCare Section 1115 Demonstration Non-Acceptance," January 22, 2019, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/me/mainecare/me-mainecare-approval-reponse-ltr-01222019.pdf.

[3] Several lawsuits are pending to overturn the requirement in Wisconsin, with Governor Tony Evers filing a brief in support of at least one of the cases. Shawn Johnson, "Fourth Lawsuit Filed Challenging Lame-Duck Laws," *Wisconsin Public Radio*, February 21, 2019, https://www.wpr.org/fourth-lawsuit-filed-challenging-lame-duck-laws.

[4] The number of enrollees fluctuated each month as individuals were phased into the requirement while others were disenrolled for failing to meet the requirement. The 79,000 figure reflects the number of beneficiaries subject to the work/CE requirement and enrolled in December 2018, plus the cumulative number disenrolled.

[5] Arkansas Department of Human Services, "ARWorks Reports," n.d., https://humanservices.arkansas.gov/newsroom/toolkits.

[6] United States Government Accountability Office, "Medicaid Demonstrations: Evaluations Yielded Limited Results, Underscoring Need for Changes to Federal Policies and Procedures," January 2018, https://www.gao.gov/assets/690/689506.pdf.

[7] Kristen Underhill, Atheendar Venkataramani, and Kevin G. Volpp, "Perspective: Fulfilling States' Duty to Evaluate Medicaid Waivers," *The New England Journal of Medicine* 379 (November 22, 2018): 1985–88, https://doi.org/10.1056/NEJMp1807370.

[8] Sara Rosenbaum et al., "Will Evaluations of Medicaid 1115 Demonstrations That Restrict Eligibility Tell Policymakers What They Need to Know?" (The Commonwealth Fund, December 12, 2018), https://www.commonwealthfund.org/publications/issue-briefs/2018/dec/evaluations-medicaid-1115-restrict-eligibility.

[9] Brian Neale, "CMCS Informational Bulletin: Section 1115 Demonstration Process Improvements" (Centers for Medicare and Medicaid Services, Center for Medicaid & CHIP Services, November 6, 2017), https://www.medicaid.gov/federal-policy-guidance/downloads/cib110617.pdf.

[10] See resources listed at: "1115 Demonstration Evaluations," Medicaid.gov, n.d., https://www.medicaid.gov/medicaid/section-1115-demo/evaluation-reports/index.html.

[11] For example, see CMS comments on Arkansas's draft evaluation plan here: Andrea J. Casart to Dawn Stehle, "Arkansas Community Engagement Section 1115 Demonstration Evaluation Design: CMS Feedback," January 11, 2018, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ar/Health-Care-Independence-Program-Private-Option/ar-works-feedback-eval-dsgn-20181101.pdf. This advice is provided in part with contractor support; see: Mathematica Policy Research, "New Approaches for Medicaid: The 1115 Demonstration Evaluation (2014 - 2018)," n.d., https://www.mathematica-mpr.com/our-publications-and-findings/projects/medicaid-1115-demonstration-evaluation.

[12] The guidance is currently being provided to individual states in draft form while it undergoes the federal review and approval process.

[13] "Evaluation of the Health and Economic Consequences of Kentucky's Section 1115 Demonstration Waiver," ClinicalTrials.gov, February 15, 2019, https://clinicaltrials.gov/ct2/show/NCT03602456.

[14] Review of contracts available at: "Contract Search," Transparency.ky.gov, n.d., https://transparency.ky.gov/search/Pages/contractsearch.aspx#/contract.

[15] "Arkansas Works," State Waivers List, Medicaid.gov, n.d., https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/?entry=15033.

[16] Brian Neale to State Medicaid Directors, "Opportunities to Promote Work and Community Engagement Among Medicaid Beneficiaries," SMD 18-002, January 11, 2018, https://www.medicaid.gov/federal-policy-guidance/downloads/smd18002.pdf.

[17] 42 C.F.R. §§ 164.501, 164.506(c)(1), 164.512(i)(1)(i).

[18] Social Security Act § 1902(a)(7).

[19] HIPAA permits covered entities such as state Medicaid programs to use their own data for purposes of "health care operations," which includes outcomes evaluation, and such data also may be used for purposes of research if an institutional review board or other privacy board has waived the requirement for patient authorization. Federal Medicaid law allows the use of identifiable Medicaid data for purposes "directly connected with the administration" of Medicaid. These laws also permit Medicaid agencies to use contractors to conduct such evaluations, though contractors may need to enter into business associate agreements and/or data sharing agreements with the Medicaid program in order to receive such data.

[20] Administrator, Health Care Financing Administration, Administrator, Health Resources and Services Administration, and Director, Centers for Disease Control and Prevention to State Health Officers and State Medicaid Directors and State Health Officials and State Medicaid Directors, "Facilitating Collaborations for Data Sharing between State Medicaid and Health Agencies," October 22, 1998, https://www.medicaid.gov/Federal-Policy-Guidance/downloads/SMD102298.pdf.

[21] Casart to Stehle, "Arkansas Community Engagement Section 1115 Demonstration Evaluation Design: CMS Feedback."

[22] Arkansas Center for Health Improvement, "Arkansas Health Care Independence Program ('Private Option') Section 1115 Demonstration Waiver Final Report" (Little Rock, AR, June 30, 2018), https://achi.net/wp-content/uploads/2018/01/Arkansas-Health-Care-Independence-Program-Final-Report.pdf.

[23] New York, for example, permits the disclosures of identifiable data from its APCD if the recipient has developed a plan for preventing breaches and has entered into a data use agreement subjecting the recipient of the data to liability in the case of such a breach. 10 N.Y.C.R.R. § 350.3. In Minnesota, data in the APCD is generally stripped of identifiers, and it is to be used by the Department of Health, not other agencies. Minn. Stat. § 62U.04(4).

[24] 7 C.F.R. § 272.1(c)(1)(i); 45 C.F.R. § 205.50(a)(1)(i).

[25] Although Part 2 does permit the disclosure of Part 2 data for purposes of program evaluation or research without consent in certain circumstances, given the strict nature of Part 2 rules, such information may not be included in many databases.

[26] See, for example, discussions of Wisconsin Medicaid and Marketplace data matching for waiver-related purposes here: Wisconsin Office of the Commissioner of Insurance and Wisconsin Department of Health Services, "The Wisconsin Health Insurance Market and Wisconsin Entitlement Reforms: Wisconsin's Unique Approach to Operationalizing the Affordable Care Act," March 31, 2014, https://www.dhs.wisconsin.gov/publications/p0/p00634.pdf. and Rockefeller Institute of Government, "Wisconsin: Round 1 (State-Level Field Network Study of the Implementation of the Affordable Care Act)," August 2014, https://rockinst.org/wp-content/uploads/2018/02/2014-08-Wisconsin_Round_One.pdf.

[27] Aaron McNay et al., "Montana Medicaid and Montana Employers" (Montana Department of Revenue and Montana Department of Labor & Industry, January 8, 2019), http://lmi.mt.gov/Portals/193/Publications/LMI-Pubs/Special%20Reports%20and%20Studies/MT-Medicaid_Report.pdf.

[28] Paul Mango to Carol Steckel, "Kentucky Helping to Engage and Achieve Long Term Health (KY HEALTH) Section 1115 Demonstration Approval," November 20, 2018, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ky/ky-health-ca.pdf.

[29] Average monthly enrollment was calculated using member months divided by 12. Adam Meier to Brian Neale, "Kentucky HEALTH § 1115 Demonstration Waiver Modification Request," July 6, 2017, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ky/ky-health-pa2.pdf.

[30] Eric J. Holcomb to Tom Price, "Healthy Indiana Plan Section 1115 Demonstration Waiver Amendment to Extension," July 20, 2017, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/in-healthy-indiana-plan-support-20-pa5.pdf.

[31] Michael Heifetz to Brian Neale, "Request to Amend Wisconsin's Section 1115 BadgerCare Reform Demonstration Project," July 7, 2017, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/wi/wi-badgercare-reform-pa.pdf.

[32] Christopher T. Sununu to Alex M. Azar II, "Granite Advantage Health Care Program Section 1115 Demonstration Application," July 23, 2018, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/nh/nh-health-protection-program-premium-assistance-pa4.pdf.

[33] See Appendix for additional information.

[34] Gretchen Whitmer to Seema Verma, "Healthy Michigan Plan Section 1115 Demonstration Acknowledgement and Acceptance," February 8, 2019, https://www.michigan.gov/documents/whitmer/Letter_from_Gov._Whitmer_to_CMS__645767_7.pdf.

[35] Robert Nelb, "Monitoring and Evaluating Section 1115 Demonstrations: Medicaid and CHIP Payment and Access Commission" (Medicaid and CHIP Payment and Access Commission, September 14, 2017), https://www.macpac.gov/wp-content/uploads/2017/09/Monitoring-and-Evaluating-Section-1115-Research-and-Demonstration-Waivers.pdf.

[36] Arkansas Department of Human Services, "ARWorks Reports."

[37] "Arkansas Works."

[38] See 42 C.F.R. § 431.412 and its references to the public notice process, which requires states to provide an estimate of changes in enrollment. These regulations apply to applications for new demonstrations and for extensions of existing ones. In the case of amendments to existing demonstrations, requirements are governed by the STCs that are developed by CMS for individual waivers but are frequently applied in the same or a similar manner across states; these STCs often incorporate the regulatory requirement for public notice.

[39] CMS STCs that accompany waiver approvals generally require states to submit their waiver monitoring and evaluation plans within 90 and 120 days, respectively, of waiver approval.

[40] Neale to State Medicaid Directors, "Opportunities to Promote Work and Community Engagement Among Medicaid Beneficiaries."

[41] Mango to Steckel, "Kentucky Helping to Engage and Achieve Long Term Health (KY HEALTH) Section 1115 Demonstration Approval."

[42] Mary C. Mayhew to Lipman D. Henry, "New Hampshire Granite Advantage Health Care Program 1115 Demonstration Approval," November 30, 2018, https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/nh/nh-granite-advantage-health-care-program-ca.pdf.

[43] Mango to Steckel, "Kentucky Helping to Engage and Achieve Long Term Health (KY HEALTH) Section 1115 Demonstration Approval."

[44] Mayhew to Henry, "New Hampshire Granite Advantage Health Care Program 1115 Demonstration Approval."

[45] "Arkansas Works."

[46] The number of enrollees fluctuated each month as individuals were phased into the requirement while others were disenrolled for failing to meet the requirement. A figure of 79,000 (denominator for the 23 percent) reflects the number of beneficiaries subject to the work/CE requirement and enrolled in December 2018 plus the cumulative number disenrolled, A figure of 24,000 (denominator for the 75 percent) reflects the number of beneficiaries who had a reporting obligation and no exemption in December 2018 plus the cumulative number disenrolled.

[47] Arkansas Department of Human Services, "ARWorks Reports."

[48] MaryBeth Musumeci, Robin Rudowitz, and Cornelia Hall, "An Early Look at Implementation of Medicaid Work Requirements in Arkansas," Issue Brief (Henry J. Kaiser Family Foundation, October 2018), http://files.kff.org/attachment/Issue-Brief-An-Early-Look-at-Implementation-of-Medicaid-Work-Requirements-in-Arkansas.

[49] Benjamin Hardy, "Locked Out of Medicaid: Arkansas's Work Reqirement Strips Insurance From Thousands of Working People," *Arkansas Times*, November 19, 2018, https://www.arktimes.com/arkansas/when-arkansas-works-doesnt/Content?oid=25890378.

[50] Benjamin Hardy, "Trump Administration Defends Arkansas's Medicaid Work Requirements," *Arkansas Blog* (blog), December 1, 2018, https://www.arktimes.com/ArkansasBlog/archives/2018/12/01/trump-administration-defends-arkansass-work-requirements-for-medicaid.

[51] Benjamin Hardy, "Akansas DHS to Step Up Outreach on Medicaid Work Requirement and Allow Reporting by Phone," Arkansas Blog (blog), December 12, 2018, https://www.arktimes.com/ArkansasBlog/archives/2018/12/12/arkansas-dhs-to-step-up-outreach-on-medicaid-work-requirement-and-allow-reporting-by-phone.

[52] MaryBeth Musumeci, Robin Rudowitz, and Barbara Lyons, "Medicaid Work Requirements in Arkansas: Experience and Perspectives of Enrollees," Issue Brief (Henry J. Kaiser Family Foundation, December 18, 2018), https://www.kff.org/medicaid/issue-brief/medicaid-work-requirements-in-arkansas-experience-and-perspectives-of-enrollees/.

[53] Casart to Stehle, "Arkansas Community Engagement Section 1115 Demonstration Evaluation Design: CMS Feedback."

[54] Brian Neale to State Medicaid Directors, "Strategies to Address the Opioid Epidemic," SMD 17-003, November 1, 2017, https://www.medicaid.gov/federal-policy-guidance/downloads/smd17003.pdf.

[55] Mary C. Mayhew to State Medicaid Directors, "Opportunities to Design Innovative Service Delivery Systems for Adults with a Serious Mental Illness or Children with a Serious Emotional Disturbance," SMD 18-011, November 13, 2018, https://www.medicaid.gov/federal-policy-guidance/downloads/smd18011.pdf.

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