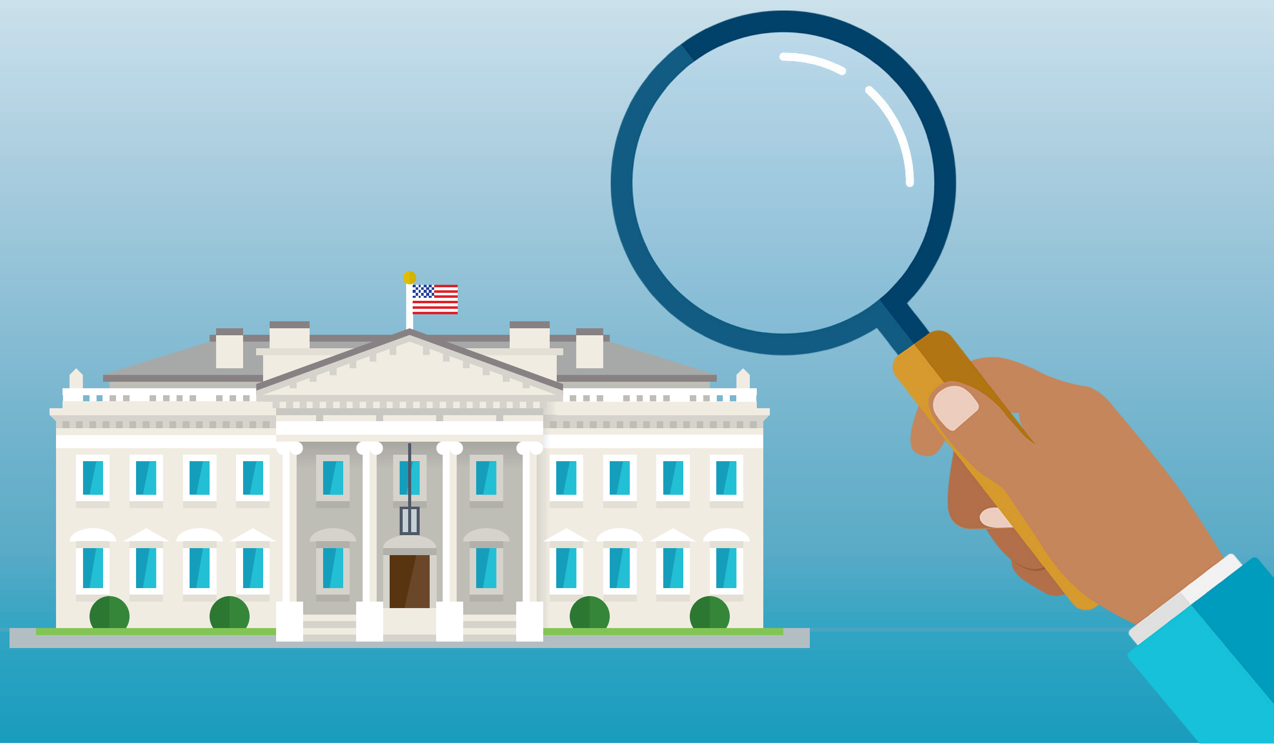
POLICY ANALYSIS PAPER

What is the Future for Medicaid HCBS Waivers as a New Federal Administration Takes Shape?



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Introduction

Nearly 100 days of the new Biden Administration have passed and captivated the imagination of America. Our nation is confronting unprecedented health challenges and fiscal uncertainties. The emergence of the COVID-19 pandemic has overwhelmed all other health policy challenges across the U.S. It also has escalated the public's attention to deeply intrenched racial disparities in health outcomes and health care and illuminated the disproportionate burdens many individuals and health care workers experience, especially people of color.

Professionals who support individuals with physical and/or intellectual disabilities (IDD) and the frail elderly are eager to learn more about what can be expected in the Biden Administration as it reviews and implements Medicaid policy for home and community-based (HCBS) waivers and 1115 demonstrations. The question is important as federal Medicaid waivers permit states to offer an array of community-based services to beneficiaries who are elderly and/or disabled so they may live safely and thrive in community settings and avoid institutionalization. As the scope of Medicaid HCBS and supports varies widely among states, indications from Washington, DC can help stakeholders prepare for a more promising – indeed, Build Back Better – future.

The crystal ball, at this writing, remains cloudy. It is obvious there is not a sufficient amount of HCBS and supports to meet the significant needs of frail elderly and/or individuals with disabilities across the USA. To clear the fog, let's offer developments and perspectives, derived from recently published sources and interviews with key observers, to illuminate what can be anticipated in the months ahead.

About the Author

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The Urgency of Now

No other health priority comes close in the new Administration to the goal of implementing solutions for eliminating the afflictions of the COVID-19 pandemic. COVID-19 will be the framework for anchoring most health policy recommendations, including HCBS, into legislative and budget proposals. Within this overall framework, expect to see more focus on improving health care access overall, including insurance coverage; reducing or eliminating health disparities; improving health quality/outcomes and data sharing; addressing workforce shortages; and encouraging innovative and improved models of services, such as telehealth and integrated care, to achieve better value for monies spent.

The hurdles of health disparities and inequitable access to care are especially acute for the 7.4 million children and adults with intellectual or developmental disabilities.

Even before the pandemic, life expectancy for people with intellectual and developmental disabilities was nearly 20 years below that of the general population.

States use a combination of federal Medicaid and state-based funding to operate programs for individuals with IDD, and these programs have grown rapidly over 35 years as individuals served have sought independence and agency over their lives. While per person expenditures are high (due to the intensity of need and supports delivered across the lifespan), notable service gaps are common. State-by-state service waiting lists are the norm before individuals can enroll into HCBS and support programs. Program silos among state agencies contribute to service gaps and poor integration. This is a serious problem for individuals with IDD as nearly one-half of them have been diagnosed with a co-occurring mental/behavioral health condition. In addition, limited individualized supports to assist men and women as they seek employment undermine their full potential and contribute to dependency. Research literature is increasingly providing evidence that people with IDD from racial, ethnic, and linguistic minorities experience further disparities in access, quality, and outcomes.[1]

[1] Health Management Associates. October 2020. Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences. Report to the Medicaid and CHIP Payment and Access Commission (MACPAC).

A recent study published in the New England Journal of Medicine[2] emphasizes the danger of COVID-19 to people with intellectual and developmental disabilities and the huge toll it has taken. People with intellectual disabilities are at significantly higher risk of contracting COVID-19 and that they will be admitted to hospitals and die there more often. Having an intellectual disability was found to be the strongest independent risk factor, other than age, for COVID-19 mortality in a cross-sectional study of nearly 65 million patients across 547 health care organizations.

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The scourge of nursing home deaths during the COVID-19 pandemic put a glaring spotlight on the health dangers facing people living in nursing homes and other institutional-like settings. This national tragedy suggests that federal policymakers will become more attuned to the importance of HCBS for vulnerable populations, such as people with disabilities and the elderly. The poor performance of nursing homes in tackling infectious disease risk is a wake-up call – fostering more interest in the use Medicaid waivers to support safe community-based long-term care and encouraging states to address disparities in the availability and delivery of services.

President Biden wasted no time in tackling the nation's urgent health crises. Unveiled during his first day as President was a national strategy for America's COVID-19 response. His top priority was to provide emergency relief, protect those most at risk, expand immunizations, mitigate the spread through public health measures, etc. Yet, he also gave a nod to HCBS proposing a significant investment in HCBS as part of "Build Back Better." The Centers for Medicare & Medicaid Services (CMS) and The Administration for Community Living (ACL) were tasked to identify opportunities and funding mechanisms for providing greater support for individuals receiving HCBS, with particular attention to people with disabilities and the home care work force.

[2] Gleason, Ross, Fossi et al. March 5, 2021. "Commentary: The Devastating Impact of COVID-19 on Individuals with Intellectual Disabilities in the United States," in New England Journal of Medicine.

American Rescue Plan Act of 2021

Federal COVID-19 relief will help HCBS in at least one important way. Across the states, Medicaid funding for HCBS is increasing. Recent passage of the $1.9 trillion COVID-19 relief package, signed into law by President Biden, is encouraging as it provides a 10 percent increase in FMAP[3] funding for Medicaid HCBS. CMS will allocate these HCBS funds to State Medicaid agencies, which then allocate the funds to enhance or expand HCBS services. States have broad discretion in how the funds can be used. The legislation requires states to “implement, or supplement the implementation of one or more activities to enhance, expand, or strengthen” their HCBS programs.

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This HCBS provision is being praised by providers and states alike, as it will encourage expansion of HCBS compared to institutional care and allow provider agencies to recover more quickly from the COVID-19 pandemic as they have lost revenues and incurred additional expenses to purchase supplies and protective equipment. Funds can be used to reduce or eliminate waiver wait lists and expand access to desired services, such as telehealth technology. Given the pandemic’s toll on the direct care workforce, the HCBS funds may be used for pay and benefit enhancements for workers, training, and other workforce development. States may want to implement pilot programs to test proof-of-concept for specific innovations. Most importantly, the additional HCBS funds will enable states to respond more effectively to the ongoing pandemic by serving people safely at home.

[3] The Federal Medical Assistance Percentages (FMAP) are the percentage rates the federal government uses to match certain state expenditures for their medical and social service programs, including Medicaid.

Other Hints of Emerging Policy Influencing Medicaid Waivers for HCBS

Early Transition Considerations

Before President Biden was elected and while running for office, his campaign proposed a $775 billion plan to overhaul the nation's caregiving infrastructure and create three million new jobs. These bold ideas would require a combination of legislative and budgetary actions, and Medicaid regulatory fixes, including waiver policy for HCBS.

Even as Biden remained laser-focused on COVID-19, his transition team recommended[4]:

- Strengthening the direct care workforce, including increasing minimum wage and providing federal funded paid leave.
- Providing tax relief for caregiving, including tax credits for informal family caregiving.
- Increasing funding for Money Follows the Person to assist individuals transitioning out of congregate settings.
- Affirming the right of individuals with disabilities to self-direct; and encouraging states to extend a self-directing person the right to hire family members.
- Fully implementing the HCBS Final Rule to ensure community-based services do not feel or look like institutional settings.
- Improving the Medicaid buy-in program so people with disabilities can work and stay on Medicaid.
- Expanding mental health and behavioral health services.
- And, perhaps most importantly, putting HCBS on equal footing with institutional settings (thus, ending institutional bias).

Some of these ideas are already finding their way into legislative proposals and executive orders.

[4] https://joebiden.com/covid19-disabilities/

New Leadership within Department of Health & Human Services (HHS)

Clues about Medicaid policy, including HCBS waivers, can be found in who President Biden has chosen to serve in his Administration.

- The Senate confirmed Xavier Becerra, California's Attorney General, to serve as HHS Secretary. He will lead a behemoth of agencies[5], all of which will be focused first on tackling the COVID-19 pandemic "so that the American people can get back to work, back to their lives, and back to their loved ones" said President Biden. Mr. Becerra was a member of the US House of Representatives for 12 terms, is experienced in leading large complex organizations, and led a passionate and articulate defense of the Affordable Care Act (ACA) last year in the Supreme Court. As California's AG, he challenged health sector consolidation and anti-competitive pricing, and backed transparency (including drug pricing), provider competition, improved health equity, and expanded use of innovative services (such as telehealth) to assure rural and underserved access to care.

- CMS' proposed new Administrator, Chiquita Brooks-LaSure, is well respected in health policy circles. She was Biden's Health Transition Team Lead and a Managing Director of Manatt Health (Manatt, Phelps & Phillips, LLC). At the helm of CMS, she will lead the largest HHS operating division (with more than 6,000 employees) and have regulatory oversight of nearly all health care providers in the nation as well as control of federal programs (such as Medicare and Medicaid) covering 145 million Americans. Ms. Brooks-LaSure played a key role in guiding the ACA through passage and implementation, and her CMS focus initially is expected to be shoring up the ACA, in addition to addressing COVID-19. For much of Ms. Brooks-LaSure's career, she has focused on regulatory and legislative policies across private insurance, Medicare, and Medicaid; state and federal health insurance markets; state strategies for advancing health equity; and consumer information.

- Another agency, albeit lesser known, that influences Medicaid and HCBS policy is the Administration for Community Living (ACL). The agency's mission is to maximize the independence, well-being, and health of older adults and people with disabilities, across the lifespan, and their families and caregivers. Alison Barkoff was sworn in as the ACL's Principal Deputy Administrator in January 2021 and serves as ACL's Acting Administrator. She is an attorney and has directed advocacy efforts in several organizations, with a particular emphasis on inclusion.

[5] Including National Institutes of Health, Centers for Medicare and Medicaid Services, Centers for Disease Control and Prevention, Food and Drug Administration, Administration for Community Living, Health Resources and Services Administration, and others.

Neither the HHS Secretary nor CMS Administrator-designee are long-term care or HCBS experts. Their appointments suggest the importance in the Biden-Harris Administration of tackling other immediate health priorities. It can be expected that all of the agency leaders will be pulled in many competing directions and that Medicaid and HCBS initiatives must be cast within a framework of COVID-19 and health equity to assure action on policy proposals.

National Association of Medicaid Directors

The National Association of Medicaid Directors (NAMD) is an important link to state Medicaid agencies (which vary considerably in size and perspective) and indirectly to constituent stakeholders. NAMD offered several recommendations to the Biden/Harris transition team to strengthen the administration of Medicaid at the state level. The recommendations were intended foremost to enhance Medicaid's ability to respond to the ongoing pandemic. Overall, NAMD continues to seek to strengthen state/federal partnership with a commitment to efficient administration, mutual accountability, and consistent communication. NAMD also highlighted its desire to advance equity in the Medicaid program, address systemic inequities, and provide better care to underserved populations, including behavioral health and long-term services and supports (LTSS). It advocated for state flexibility to innovate and called for seamless renewals of Appendix K flexibilities under 1915c waivers, including longer than one-year approval limits.

The importance of Appendix K (Emergency Preparedness and Response) waiver modifications was highlighted this past year as states sought CMS approval to alter their HCBS programs during the COVID-19 crisis. It is likely that many of the Appendix K flexibilities and innovations will continue after the pandemic has ended.

Medicaid Waivers In General

Medicaid waivers are considered important engines that support community-based long-term care, allowing people to be served at home rather than in an institution. CMS will likely scrutinize recent state waivers with extra care, minimizing the extent to which they provide a precedent for future waiver approvals (e.g. work requirements). Several states have expressed interest in pursuing 10-year waiver approvals (e.g. TN, FL, TX), but the position of the Biden Administration is unclear about this time frame. It is possible that states may be approved to extend existing waivers for long periods if they have demonstrated results, yet CMS is unlikely to allow such a long waiver period for new or untested provisions.

There will likely be a continued focus on "the duals," those 12.2 million beneficiaries who have both Medicare and Medicaid coverage. Medical and long-term care services for the dual population consume one-third of all Medicare and Medicaid funds. This dual population is

vulnerable with high rates of chronic illness, mental illness, and disabilities. CMS will continue, even accelerate, its commitment to facilitate better care for dually eligible individuals. It will continue to encourage states to promote integrated care through Medicaid managed care, PACE, D-SNPs, and Medicare Advantage options. Policymakers generally agree that better managed care can offer a more holistic and integrated approach across providers, sharing risk and reward for the HCBS population. At the same time, expect more scrutiny by CMS and the states of managed care performance concerning the delivery of long-term services and supports.

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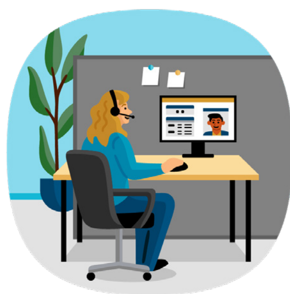
Some have suggested CMS may liberalize the use of Medicaid waiver funds for broader health-related initiatives, especially if it is done so in a manner consistent with Administration priorities for the Medicaid program (e.g. addressing COVID-19, reducing disparities and racial inequities in health care and outcomes). With more focus on equitable access to HCBS and supports and rejection of policies that perpetuate structural racism in community-based care, it remains uncertain how political and stakeholder resistance can be overcome and how multi-sector collaboration will be fostered to achieve improved equity through waiver requirements.

Considerations for CMS Leadership

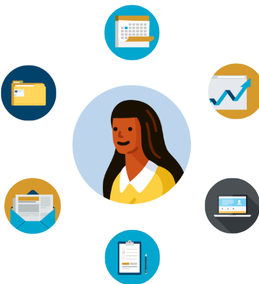
During the past two months, an outpouring of ideas have been published by health policy experts and HCBS stakeholders suggesting ways that HCBS can be strengthened – through Medicaid waivers and/or legislation. Some issues that have attained traction include:



Overcoming the digital divide. Since so much health care has been delivered virtually during the pandemic, an area of increasing urgency is helping people bridge the digital divide for their HCBS and supports. Telemedicine and telehealth technology are increasingly being used for primary care (to avoid unnecessary emergency room use), socialization, habilitation, and managing chronic diseases and promoting behavior change. The transition to telemedicine and virtual services in place of in-person support has helped expand care to millions and increased the independence of those with IDD. Yet, without the skills, resources, and supports to get online and participate in digital forums, many older adults and people with disabilities are more isolated than ever. The need is growing for person-centered technology support, dependable Internet access, and funds for laptops or other devices among individuals serviced by HCBS programs.

The public has been shocked by inconsistent and incomplete data reporting during COVID-19 and are wondering, “What are trusted facts and what is fake news?” Public officials and providers, too, have been frustrated. Thus, increasing attention will be paid to **data sharing, quality monitoring, and infectious disease control** post COVID-19, reducing agency program and data silos, and aligning federal and state systems and expectations. CMS has been encouraged to enhance states’ critical incidence reporting to protect the health and welfare of Medicaid beneficiaries receiving waiver services, and to offer more guidance and training.

Stakeholders continue to advocate for improved **wages and benefits** for direct care professionals who deliver HCBS and supports. There’s wide consensus that HCBS programs must do a better job of tackling staff turnover, direct care worker shortages, and uneven service quality as well. All of this may be difficult to accomplish given uncertainty about raising the minimum wage at federal level.



Self-direction continues to be considered an important option for individuals receiving HCBS and is most effective when there are robust supports to assist people in managing their plans and services. State waiver language and managed care contracts will increasingly be reviewed to determine best practices for attaining robust self-directed supports and services among individuals with Medicaid coverage, including those receiving behavioral health services.

At some point as the nation recovers from the COVID-19 pandemic, there will be increased pressure within CMS and other agencies, and among state and national officials, to better manage Medicaid and other health payer costs and achieve higher value for public funds that are being expended. Many states are experiencing a budget shortfall (and some significant deficits) due to unanticipated expenditures and revenue shortfalls due to COVID-19. There is no consensus about what this **financing reform** should look like or how it can be achieved.

Conclusion

The federal health policy landscape will be shaped over the next few years by a proactive Executive Branch, with agencies headed by experienced leadership, and by a narrowly Democratic-controlled Senate and House. Important to Medicaid waiver administration, at the state level, Republicans control 28 and Democrats control 22 governorships. CMS will be asked to use its waiver and demonstration authorities to achieve on a smaller scale what cannot be accomplished in Congress. It can be expected to work with interested states to test out promising ideas for improving the lives of and community support for individuals with disabilities and chronic conditions. What the immediate future holds for Medicaid waivers is not yet clear. It is possible, however, that the Biden Administration could become the "golden age" of innovative waiver design under Medicaid.

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