REPORT 4 OF THE COUNCIL ON MEDICAL SERVICE (NOV-21)
Financing of Home and Community-Based Services
(Reference Committee G)

EXECUTIVE SUMMARY

The Council on Medical Service initiated this report to provide an overview of the current financing mechanisms for home and community-based services (HCBS) and to raise awareness about the importance of identifying sustainable methods of broader long-term services and supports (LTSS) financing. This report builds on the long-standing policy of the American Medical Association (AMA) regarding LTSS and presents policy recommendations to modify the current financing structure of HCBS.

The United States (US) is undergoing a population shift. By 2040, about one in five Americans will be 65 or older. By 2050, those over age 85 are projected to more than triple, and it is estimated that 70 percent of seniors reaching age 65 are expected to require some type of long-term care (LTC) assistance in their lifetime. LTC includes both medical and non-medical care, such as assistance with activities of daily living (ADLs). ADLs include a range of activities such as help with bathing, dressing, meal preparation, medication management, housekeeping, and transportation. Hundreds of thousands of older and disabled individuals live in institutionalized care settings not because they need the level of specialized medical care provided in those settings, but because Medicaid payment rules make that the only option with daily care that they can afford. The current LTSS financing structure and incentives generally favor expensive institutional care settings like skilled nursing facilities over less expensive and usually more desirable care settings like adult day care and home care. However, under the Medicaid statute, states must cover institutional LTSS services, but covering HCBS like home health aides and adult day care is optional. Therefore, Medicaid coverage for services in the home or community varies by state with some states not offering HCBS altogether.

Concurrent with demographic shifts, the COVID-19 pandemic has exposed the vulnerabilities of institutionalized care settings such as LTC facilities and the weaknesses in the nation’s system of caring for older adults and individuals with disabilities and limitations. It is estimated that nursing home deaths are believed to account for about one-third of total COVID-19 deaths. This grim reality has highlighted the need for a better system of caring for these older and disabled populations.

The Council believes the AMA should seize this opportunity to rethink the current long-term care system and to build upon the AMA’s current body of long-term care policy to recommend fundamental reforms, specifically reforms strengthening the nation’s system of HCBS. HCBS presents a compelling shift away from institutionalized care. Not only is there currently an unmet need for HCBS, but also, this need is expected to increase with a growing elderly population. Through the Council’s set of recommendations, states and the federal government are encouraged to develop and expand HCBS offerings as lower-cost and more preferred alternatives to providing institutional care.
The COVID-19 pandemic has exposed the vulnerabilities of institutionalized care settings such as long-term care (LTC) facilities and the weaknesses in the nation’s system of caring for older adults and individuals with disabilities and limitations. It is estimated that about eight percent of people living in LTC facilities have died of COVID-19, a percentage that is considered an undercount. In particular, nursing home deaths are believed to account for about one-third of total COVID-19 deaths. This grim reality has highlighted the need for a better system of caring for these older and disabled populations. The Council recognizes that COVID-19 pandemic has created an opportunity to review the current LTC system and to build upon the American Medical Association’s (AMA’s) current body of LTC policy to recommend fundamental reforms, specifically reforms strengthening the nation’s system of home and community-based services (HCBS).

This report, initiated by the Council, provides an overview of LTC needs in the United States (US), highlights the myriad ways that HCBS is funded, outlines current HCBS legislative proposals, summarizes relevant AMA policy, and recommends policy to create a stronger foundation and financing structure for HCBS.

BACKGROUND

The US is undergoing a population shift. By 2040, about one in five Americans will be 65 or older. By 2050, those over age 85 are projected to more than triple. According to the US Department of Health and Human Services (HHS), 70 percent of seniors reaching age 65 are expected to require some type of LTC assistance in their lifetime. LTC includes both medical and non-medical care, such as assistance with activities of daily living (ADLs). ADLs include a range of activities such as help with bathing, dressing, meal preparation, medication management, help with housekeeping, and transportation.

Hundreds of thousands of older and disabled individuals live in institutionalized care settings not because they need the level of specialized medical care provided in those settings, but because Medicaid payment rules make that the only option with daily care that they can afford. The current long-term services and supports (LTSS) financing structure and incentives generally favor expensive institutional care settings like skilled nursing facilities over less expensive and usually more desirable care settings like adult day care and home care. The average annual cost for a nursing home room is $105,850. Alternatively, the average annual cost for a full-time home health aide is about $48,000, and the cost of adult day care is about $17,000. However, under the Medicaid statute, states must cover institutional LTSS services, but covering HCBS like home health aides and adult day care is optional. Therefore, Medicaid coverage for services in the home or community varies by state with some states not offering HCBS altogether. According to
Congressional Budget Office projections, federal LTSS expenditures under Medicaid are projected
to reach $113 billion per year by 2025 compared with the $74 billion spent in 2014.\textsuperscript{7}

Many residents in institutional facilities only need assistance with ADLs, and many would prefer to
be living in their own communities. Seventy-six percent of people aged 50 and older would prefer
to remain in their home for as long as possible, and 90 percent would prefer to age in place either in
their homes or community settings such as adult day care centers.\textsuperscript{8} Access to HCBS has emerged
as an alternative to institutionalized care settings to help older Americans and those with
disabilities live independently while receiving assistance with daily needs.

Medicaid beneficiaries with LTSS needs account for 6.4 percent of the Medicaid population but
45.6 percent of Medicaid expenditures.\textsuperscript{9} Exacerbating the financial challenge of providing LTSS
care to an aging population is a significant birth decline. The latest US census revealed that the US
has one of the slowest rates of population growth in decades. The decline is largely due to
deleing immigration and a declining birthrate, which means there will continue to be fewer
workers to support the aging population.\textsuperscript{10} Today, there are 2.8 workers per Medicare beneficiary.
However, that number is expected to decline to 2.3 workers by 2030.\textsuperscript{11} This demographic shift puts
a substantial strain on state and federal budgets and causes great instability in the programs on
which the elderly and disabled rely. Therefore, it is critical to explore financially stable alternatives
to providing LTSS to this population. In keeping people out of more expensive institutions and in
the community, HCBS provides one method to stabilize LTSS funding.

MECHANISMS TO PROVIDE HCBS FINANCING AND SERVICES

\textit{Section 1915(c) and Section 1115 Waivers}

For the last 40 years, states have used waivers to provide HCBS to Medicaid beneficiaries. Nearly
all HCBS beneficiaries receive services through an optional authority. Section 1915(c) of the
Social Security Act authorizes a waiver program allowing states to meet the care needs of their
populations through LTSS in their homes or communities rather than in an institutional care
setting. Section 1115 waivers give states the option to waive certain Medicaid requirements and
allow states to use Medicaid funds for pilot or demonstration projects.\textsuperscript{12} For example, states can
target waivers to areas of the state where need is the greatest. States can also make waiver services
available to certain groups of people who are at risk of institutionalization, such as those with a
particular diagnosis. States can provide Medicaid to people who would otherwise only be eligible
for coverage in an institutional setting. Using their waiver authority, states are permitted to offer a
variety of services. Therefore, states can use waivers to provide a combination of standard medical
and non-medical services. Services may include case management, home health aides, personal
care, adult day care centers, and respite care. Moreover, states can implement other types of
services that may assist in diverting or transitioning individuals from institutional care settings.\textsuperscript{13,14}

Nearly all states and DC offer services through HCBS waivers. However, states continue to face an
arduous federal waiver process. Obtaining a waiver generally requires negotiations between states
and the federal government. There currently are more than 300 HCBS waiver programs in effect
nationwide. Relying upon such a patchwork system makes the availability of HCBS services highly
dependent on the state in which a beneficiary resides.\textsuperscript{15}

\textit{State Plan Amendments}

A Medicaid state plan is an agreement between the state and the federal government detailing how
the state administers its Medicaid program. In it, the state attests that it will follow federal rules and
States can amend their plans through a state plan amendment (SPA). States can submit a proposed SPA to Centers for Medicare & Medicaid Services (CMS) for review and approval. Over the years, Congress has enacted several SPAs designed to make it easier for states to expand HCBS. Using an SPA, states can provide Medicaid to people who would otherwise only be eligible for coverage in an institutional setting. States can also target services to individuals with particular needs, risk factors, or those with a specific disease or condition.

Money Follows the Person

Medicaid’s Money Follows the Person (MFP) demonstration has been in place since 2008. The initiative’s intent is to rebalance Medicaid’s bias for institutional care and seek to move seniors and people with disabilities from institutions and into the community. The program uses enhanced federal matching funds to incentivize states to operationalize the program. Since its inception, the MFP program has helped more than 100,000 individuals transition from institutional to community care settings. Notably, the national MFP program evaluation found that enrollees experienced significant increases in quality-of-life measures after transitioning back to their communities. The evaluation also found that some individuals would not have made the transition away from institutional care if not for MFP. The program also helped states control spending, which is attributed to the fact that HCBS typically costs less than institutional care. The evaluation found that state Medicaid programs saved about $978 million during the first year after transition for MFP enrollees. The availability of the program relies on federal funding reauthorization, which is set to expire in 2023.

Federal Medical Assistance Percentages

The Federal Medical Assistance Percentages (FMAPs) are used to determine the federal share for most Medicaid health care services. It is calculated by a formula that is designed so that the federal government pays a larger portion of Medicaid costs in states with lower per capita incomes compared to the national average. For example, the FMAP rate in Mississippi is 84.51 percent while the rate in Massachusetts is 56.2 percent.

The FMAP is critical to the provision of Medicaid services in states. Medicaid accounts for nearly 30 percent of state budgets, and state budgets are particularly constrained due to the economic strain of the COVID-19 pandemic. State budgets require Medicaid predictability and limiting the number of beneficiaries and services allows states to accurately estimate HCBS expenditures. Absent increased federal matching funds, states are unlikely to expand HCBS services and eligibility despite significant unmet need.

WORKFORCE

A key barrier to meaningful expansion of HCBS is an unstable workforce. States regularly mention workforce shortages as an obstacle to expanding HCBS, and the shortages have only been exacerbated by the COVID-19 pandemic. Currently, there are about 4.5 million direct care workers (DCWs) providing care to older adults and individuals with disabilities. Between 2019 and 2029, the Bureau of Labor Statistics estimates a 1.9 million increase in family caregiving jobs, which represents a 37 percent increase in over 10 years. The expected increased demand for DCWs is more than any other occupation in the economy.
The current workforce is primarily comprised of women of color who earn low wages and do not receive employee benefits such as paid leave, health care, job training, or advancement opportunities. On average, DCWs make about $16,200 per year. Despite their valuable work, one in eight DCWs lives in poverty. Due to these suboptimal benefits and demanding working conditions, DCW turnover is about 60-80 percent annually.

Additionally, the current workforce lacks standardization, which could provide beneficiaries with more consistent and reliable care. The federal government currently requires nursing home and home health aides to undergo 75 hours of training before they can provide care, and some states do not require personal care aides certified through Medicaid to be trained at all. Moreover, certification often costs DCWs hundreds of dollars, and three-quarters of the workforce earn less than the average state living wage. The financial obstacle requirements exemplify the lack of consideration and value placed on a critical workforce.

As of 2018, Medicare’s conditions of participation formally recognize home health aides as members of the interdisciplinary care team who are expected to report on a beneficiary’s change in condition. Despite this responsibility, little has been done to help integrate aides into care teams. This lack of team integration is unfortunate because home health aides could demonstrate value on care team models including post-acute home care, hospital at home, and ambulatory case management.

FEDERAL AGENCIES AND HOME AND COMMUNITY-BASED SERVICES

The current administration of HCBS services relies on five federal agencies. The agencies include the CMS, the Administration on Aging, the Department of Housing and Urban Development, the Department of Transportation, and the Department of Agriculture. Collectively, the agencies fund multiple programs that aid the elderly population with services like nutrition assistance, in-home care, affordable housing, and transportation.

The Older Americans Act of 1965 requires HHS’s Administration on Aging to facilitate cross-agency collaboration to administer HCBS. However, a recent US Government Accountability Office (GAO) report found that the five agencies operate largely independently of one another with minimal collaboration. The GAO’s report studied interagency collaboration and found that, though cross-agency collaboration is important for federal efforts, limited resources and competing priorities can preclude cooperation.

HOSPITAL AT HOME

Several countries pay for delivering services equivalent to hospital inpatient care to patients in their own homes. These “hospital at home” services have been successful in allowing patients with specific conditions that qualify for inpatient care to receive services in the home and avoid the risks associated with inpatient admission. Patients with conditions such as congestive heart failure, chronic obstructive pulmonary disease, and cellulitis are often candidates for the model. Patients must be sick enough to be hospitalized but stable enough to be treated at home. The at-home care is provided by visiting physicians, nurses, and other clinical staff. The services are more intensive than can be supported through traditional home health care payments. The care model has been shown to reduce costs, improve patient outcomes, and enhance the patient experience.

Although some hospitals in the US have been delivering hospital at home care and some Medicare Advantage plans are paying for it, the service is difficult to sustain or expand without payment from Medicare because a minimum number of patients need to participate for the service to be
cost-effective. The Physician-Focused Payment Model Technical Advisory Committee has recommended two different “hospital at home” payment models to HHS, but neither has been implemented to date.31

The pandemic has highlighted the flaws of institutionalized care and accelerated the availability of hospital at home. During the pandemic, CMS has allowed hospitals to deliver services in non-traditional settings, and it pressed many private insurers to do the same. The CMS program, the Acute Hospital Care at Home Program, gives participating hospitals the ability to reduce inpatient volume by treating certain acute care patients at home using a telehealth platform that allows for daily check-ins and monitoring. Telehealth has been successfully employed in the care model to help transition patients away from institutional care settings, and the technology has greatly assisted physicians and patients at a time when maintaining physical distance is critical to health and safety. The Brigham and Women’s Hospital was one hospital to take advantage of CMS’s program. A 95-day study took place evaluating the model, which cared for 65 acutely ill patients. Throughout the study, the hospital at home program was staffed by one physician, one or two nurses, and one mobile integrated health paramedic. The study showed that the program cost a fraction of the cost of caring for patients in the hospital and that such programs can serve as complements to traditional hospital-based care.32 However, it is unclear whether CMS’s Hospital Care at Home Program will be extended after the COVID-19 public health emergency ends.

In May 2021, Mayo Clinic and Kaiser Permanente announced that they were teaming up to scale the hospital at home model. The two health care giants join a growing list of hospitals around the country that have implemented this model of care. It is estimated that 30 percent of hospitalized patients can benefit from the hospital at home model.33,34

AMA POLICY

Policy H-280.945 was established with the adoption of CMS Report 5-A-18 on the financing of LTSS. The policy states that our AMA supports policies that standardize and simplify private long-term care insurance (LTCI) to achieve increased coverage and improved affordability; supports adding transferable and portable LTCI coverage as part of workplace automatic enrollment with an opt-out provision potentially available to both current employees and retirees; supports allowing employer-based retirement savings to be used for LTCI premiums and LTSS expenses, including supporting penalty-free withdrawals from retirement savings accounts for purchase of private LTCI; and supports innovations in LTCI product design, including the insurance of HCBS and the marketing of LTC products with health insurance, life insurance and annuities. The policy also supports expanding LTSS benefits by permitting Medigap plans to offer a limited LTSS benefit as an optional supplemental benefit or as a separate insurance policy and Medicare Advantage plans offering LTSS in their benefit packages. In addition, the policy supports permitting Medigap and Medicare Advantage plans to offer a respite care benefit as an optional benefit and supports a back-end public catastrophic LTCI program. Particularly salient to this report, the policy also supports incentivizing states to expand the availability of and access to home and community-based services and calls for better integration of health and social services and supports, including the Program of All-Inclusive Care for the Elderly.

Policy H-280.991 addresses financing of LTC and outlines relevant principles and policy proposals for LTC. It states that programs to finance LTC should cover needed services in a timely and coordinated manner in the least restrictive setting appropriate to the health care needs of the individual and coordinate benefits across different LTC financing programs. The policy suggests providing coverage for the medical components of LTC through Medicaid for all individuals with income below 100 percent of the poverty level and providing sliding scale subsidies for the
purchase of LTCI coverage for individuals with income between 100-200 percent of the poverty level. Policy H-290.958 supports increases in states’ FMAPs or other funding during significant economic downturns to allow state Medicaid programs to continue serving Medicaid patients and cover rising enrollment.

Policy H-280.991 supports tax incentives and employer-based LTC coverage to help fund LTC including creating tax incentives to allow individuals to prospectively finance the cost of LTC coverage and encouraging employers to offer such policies as a part of employee benefit packages and otherwise treat employer-provided coverage in the same fashion as health insurance coverage and allow tax-free withdrawals from Individual Retirement Accounts and Employee Trusts for payment of LTCI premiums and expenses. Additionally, the policy supports the use of a tax deduction or credit to encourage family caregiving. Policy H-280.991 states that consumer information programs should be expanded to emphasize the need for funding anticipated costs for LTC and to describe the coverage limitations of Medicare, Medicaid, and traditional Medigap policies. State medical associations should be encouraged to seek appropriate legislation or regulation in their jurisdictions to provide an environment within their states that permit innovative LTC financing and delivery arrangements and assure that private LTC financing and delivery systems, once developed, provide the appropriate safeguards for the delivery of high-quality care. Additionally, consistent with other AMA policy on state-based innovation, Policy H-280.991 supports health system reform legislative initiatives that could increase states’ flexibility to design and implement long-term care delivery and financing programs.

Policy H-290.982 supports allowing states to use LTC eligibility criteria that distinguish between persons who can be served in a home or community-based setting and those who can only be served safely and cost-effectively in a nursing facility. Such criteria should include measures of functional impairment that account for impairments caused by cognitive and mental disorders and measures of medically related LTC needs. The policy supports buy-ins for home and community-based care for persons with incomes and assets above Medicaid eligibility limits and supports providing grants to states to develop new LTC infrastructure and to encourage expansion of LTC financing to middle-income families who need assistance.

CURRENT HCBS PROPOSALS

In Spring 2021, the Biden Administration announced a $400 billion plan to expand Medicaid HCBS and support home care workers as part of his American Jobs Plan infrastructure package. The plan does not increase funding for non-Medicaid programs critical to living at home, and it does not help middle-income Americans who make too little to pay for LTCI but earn too much to qualify for Medicaid. However, the plan proposes extending and expanding the MFP program.

Subsequently, in June 2021, a bipartisan congressional team introduced the Better Care Better Jobs Act, which would expand HCBS. The legislation formed the basis of President Biden’s $400 billion plan to expand HCBS access. A main provision of the bill calls to permanently increase the FMAP by 10 percent. To receive the increase, states would have to address payment rates to promote the recruitment and retention of DCWs. Another key provision would make the MFP program permanent.

However, in late June 2021, President Biden agreed to forego his $400 billion plan to expand HCBS as a concession to reach a deal with congressional leaders on a broader infrastructure bill. Nonetheless, a scaled-back iteration of the $400 billion plan may be incorporated into the $3.5 trillion 2022 domestic spending reconciliation bill that will be considered in Fall 2021, and provisions of the Better Care Better Jobs Act are anticipated to be included.
DISCUSSION

As the US population ages, beneficiary preferences evolve, and demographic shifts continue, HCBS provides a desirable and cost-effective way of delivering LTSS to seniors and those with disabilities. State Medicaid programs will confront increasing pressure to meet the LTSS needs of an aging population. Meanwhile, the COVID-19 pandemic has exposed the vulnerabilities of institutionalized care settings such as nursing homes and represents an opportunity to expand HCBS. The Council believes the AMA should seize this moment to establish fundamental policy to address the fractured LTSS system through a multi-pronged approach. The Council notes that this important issue is relevant to Council on Medical Service Report 1-NOV-21, which specifically addresses end of life payment. Notably, CMS Report 1-NOV-21 recommends supporting Medicare coverage of supportive care services, including assistance with activities of daily living, under Medicare’s hospice benefit, and appropriate payment for those services.

Acknowledging the AMA’s existing policy on LTSS and laying the foundation for new recommendations, the Council recommends reaffirming Policy H-280.945. The policy provides a comprehensive set of principles to improve the financing of LTSS and supports incentivizing states to expand the availability of and access to HCBS. Recognizing the importance of federal matching funds to the continuation and expansion of LTSS services, the Council also recommends reaffirming Policy H-290.958 supporting increases in states’ FMAP or other funding during significant economic downturns to allow state Medicaid programs to continue serving Medicaid patients and cover rising enrollment.

Moreover, the Council recommends that states simplify their state plan options and Medicaid waivers to allow states additional flexibility to offer HCBS. By streamlining the current patchwork system of HCBS waivers and SPAs, states could promote infrastructure development, increase administrative efficiency, improve budget predictability, and better care for beneficiaries. The Council believes that continued use of CMS waiver templates is a positive step forward. Streamlining state plan options and waivers can help eliminate Medicaid’s bias for institutional care and provide states the flexibility to offer services that better meet the needs of their populations.

The Council also recommends that Medicaid’s MFP program, set to expire in 2023, be extended or made permanent. Doing so would enable states to expand the settings that qualify as community care settings, create broader eligibility pathways, and offer new HCBS benefits. The program has demonstrated that it saves state Medicaid programs money and provides increased and sustained enrollee quality-of-life. The Council believes that the program has made important contributions to the rebalancing of LTSS away from institutional settings and into community settings and believes that these state efforts should be continued with the requisite support.

Investing in the HCBS workforce is critical to meeting the needs of an aging population and modernizing the LTSS system. To address the needs of this aging population and to support the needed caregivers, the Council recommends supporting federal funding for payment rates that promote access and greater utilization of HCBS. The Council also recommends supporting policies that help to train, retain, and develop the HCBS workforce. Steps must be taken to professionalize the HCBS workforce. The Council notes that the training and skills required will vary yet workforce standardization is critical. For example, the skills required to care for a hospital at home patient will differ from the skills required to care for an adult needing basic ADL assistance. HCBS workforce reforms would help build a pipeline of workers while stabilizing the workforce and improving quality of care. Ultimately, HCBS and LTSS reforms will only be effective if the supporting workforce is invested in and valued. Increased federal funding for payment and policy
changes to promote the workforce will help serve the needs of individuals in the most appropriate care settings.

The Council believes that strategic coordination between the five federal agencies that fund and implement HCBS activities could ensure that resources are being used efficiently and effectively for not only the government but also for beneficiaries. Accordingly, the Council recommends supporting cross-agency and federal-state strategies that can help avoid disconnects among HCBS programs and streamline funding and the provision of services. To further streamline programs, the Council recommends that HCBS programs track protocols and outcomes. Doing so could help make meaningful comparisons across states and identify best practices. It can also help promote quality care and ensure that care is aligned with patient goals.

Finally, the hospital at home model is an important component of the shift away from institutionalized care and has been successful in allowing patients with particular conditions to remain in their homes and avoid risks associated with inpatient admission and care. Accordingly, the Council recommends that CMS and private insurers offer flexibility to implement hospital at home programs for the subset of patients who meet the criteria.

HCBS presents a compelling shift away from institutionalized care. Not only is there currently an unmet need for HCBS, but also, this need is expected to increase with a growing elderly population. States and the federal government should be encouraged to develop and expand HCBS offerings as lower-cost and more preferred alternatives to providing institutional care.

RECOMMENDATIONS

The Council on Medical Service recommends that the following be adopted and the remainder of the report be filed:

1. That our American Medical Association (AMA) support federal funding for payment rates that promote access and greater utilization of home and community-based services (HCBS). (New HOD Policy)

2. That our AMA support policies that help train, retain, and develop an adequate HCBS workforce (New HOD Policy)

3. That our AMA support efforts to simplify state plan amendments and Medicaid waivers to allow additional state flexibility to offer HCBS. (New HOD Policy)

4. That our AMA support that Medicaid’s Money Follows the Person demonstration program be extended or made permanent. (New HOD Policy)

5. That our AMA support cross-agency and federal-state strategies that can help improve coordination among HCBS programs and streamline funding and the provision of services. (New HOD Policy)

6. That our AMA support HCBS programs tracking protocols and outcomes to make meaningful comparisons across states and identify best practices. (New HOD Policy)

7. That our AMA support that the Centers for Medicare & Medicaid Services and private insurers extend flexibility to implement innovative programs including but not limited to hospital at home programs. (New HOD Policy)
8. That our AMA reaffirm Policy H-280.945, which provides a comprehensive set of principles to improve the financing of long-term services and supports and supports incentivizing states to expand the availability of and access to HCBS and permitting Medigap and Medicare Advantage plans to offer a respite care benefit. (Reaffirm HOD Policy)

9. That our AMA reaffirm Policy H-290.958 which supports increases in states’ Federal Medical Assistance Percentages or other funding during significant economic downturns to allow state Medicaid programs to continue serving Medicaid patients and cover rising enrollment. (Reaffirm HOD Policy)

Fiscal Note: Less than $500.
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