

By Salom Teshale, Wendy Fox-Grage and Kitty Purington

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Summary

Family members provide significant amounts of care to relatives with complex needs, including those who are Medicaid enrollees. Medicaid enrollees may hesitate about receiving care in congregate care settings, particularly during the COVID-19 pandemic, but may face home-based care service workforce shortages. Programs that incorporate family members who provide care can help support person-centered care for Medicaid enrollees and also help states address the demand for long-term services and supports. States have the opportunity to use Medicaid to support enrollees with long-term care needs and their families by developing consumer direction programs that allow family members to be hired to provide care. This report explores how Connecticut, Florida, and Virginia developed consumer-directed care programs to serve older adults and people with physical disabilities.

Introduction

COVID-19 has upended states' long-term services and supports (LTSS) systems and strained congregate care facilities. A recent report suggests virtually all states have seen a significant drop in skilled nursing facility occupancy rates. The increasing demand for home-based care is exacerbating underlying challenges, such as long-standing LTSS direct care workforce shortages and gaps in meeting the needs of communities of color and speakers of different

languages. To address these challenges, states are exploring how Medicaid options can support enrollees with long-term care needs through consumer direction programs (also called consumer-directed care programs, participant direction programs, or

Medicaid consumer-directed care programs are an alternative way individuals can receive home-based services. Consumers choose and hire their care providers rather than having an agency dictate who delivers care.

self-direction programs) that allow family members to be paid for providing care. States have developed and expanded consumer direction programs over the past decades. Given increasing interest in home-and community-based care over institutional care, consumer direction programs are a growing option to offer older adults and people with disabilities an alternative to institutionalization. This report highlights three states' self-directed care programs that include older adults and people with physical disabilities.

Medicaid-funded consumer direction programs allow enrollees to directly hire people, including some family members, to provide personal care, such as bathing, dressing, and toileting.

<u>Findings</u> suggest consumer-directed programs can improve quality of life and health outcomes and can help meet participant needs without increasing Medicaid fraud.

According to the National Council on Disability, consideration of consumer-directed personal care options began in the late 1960s and 1970s with calls for increased autonomy and independence by and for people with disabilities. While early pilot programs focused on people with disabilities, the model – and its core values of autonomy and dignity – has since been applied to programs for older adults. Findings from the Cash and Counseling Demonstration Program suggest consumer-directed programs can improve quality of life and health outcomes and can help meet participant needs without increasing Medicaid fraud. While small-scale studies have shown savings, states can also incorporate cost-containment mechanisms into these models through waiver enrollment or spending caps, or reimbursement methodologies that limit consumer-directed care payment to a percentage of agency rates.

States are increasingly using consumer-directed models; according to <u>Applied Self-Direction</u>, all 50 states and Washington, DC have at least one consumer direction LTSS option. Several <u>Federal initiatives and CMS guidance beginning in the early 2000s</u>, the Deficit Reduction Act of 2005, and creation of the Community First Choice state plan option under the Affordable Care Act have expanded states' ability to provide these programs. This trend is likely to continue as states:

- Seek to address issues raised by the COVID-19 pandemic;
- Promote equity and access to services in underserved communities; and
- Address growing work force shortages.

Modifying or expanding consumer-directed programs can be an important strategy.

How States Can Develop Consumer-Directed Programs

States have multiple decision points when developing a Medicaid consumer-directed program. **Medicaid Authority:** States can use various Medicaid authorities to support consumer-directed options that allow family members to receive reimbursement for providing care. Policymakers have many factors to consider when designing these waivers and/or state plan amendments, such as whether to expand Medicaid eligibility, whether to target specific populations or geographic areas, and what services and supports should be provided.

The <u>majority of states</u> operate consumer-directed programs through the Medicaid 1915(c) home- and community-based waiver (HCBS) authority. Using 1915(c) waivers, states can modify eligibility requirements, target services to particular areas of the state, and/or limit or tailor services to certain populations, such as older adults or adults with physical disabilities who are at risk of institutionalization. States can, depending on the authority, add self-direction options for different services into a single waiver.

Chart: Medicaid Authorities and Consumer-Direction Options

Medicaid authority	Is institutional level of care required?	Can states waive comparability?	Can states waive statewideness?	Financial management services required?	Budget authority/ cash payments allowed?	Limits on reimbursing family caregivers
1905 (a) (24) state plan personal care services	As medically necessary	No	No	Only fiscal employer agent required	Neither budget authority nor cash payments are allowed	Excludes "legally responsible individuals"
1915(c) Home and Community-Based Services Waiver	Yes	Yes	Yes	Yes	Budget authority is allowed, but cash payments are not	Allows relatives, legally responsible individuals, and legal guardians
1915 (i) Home and Community-Based Services state plan option	No (allows individuals with less than institutional level-of-care requirements depending on certain types of eligibility)	Yes	No	Yes	Budget authority is allowed but cash payments are not	Allows relatives, legally responsible individuals, and legal guardians
1915(j) self-directed personal assistance services state plan option	No, if receiving services through state plan and state plan does not require it Yes, if receiving services through a 1915 (c) waiver	Yes	Yes	Yes, unless participants choose to receive cash directly	Budget authority is required, cash payments are allowed	Allows legally responsible relatives
1915(k) Community First Choice State Plan Option	Yes	No	No	Yes, depending on the model selected	States may allow budget authority and cash payments to participants depending on the model selected	Allows legally responsible individuals, relatives
1115 Demonstration Waiver	Determined by state	Determined by state	Yes	Yes, when incorporating participant-direction	States may allow budget authority and cash payments to participants	Allows legally responsible individuals, relatives

Sources:

Authority Comparison Chart. HCBS Technical Assistance Web Site. Center for Medicare and Medicaid Services. Accessed Dec. 31, 2020. Home and Community Based Services Authorities. Medicaid.gov. Centers for Medicare and Medicaid Services. Accessed Dec. 31, 2020. Self-Directed Services, Medicaid.gov (Centers for Medicare and Medicaid Services), accessed Dec. 31, 2020. Participant Direction Features of the Optional Medicaid Authorities, Table 7-1, p. 182. O'Keeffe, Janet, Paul Saucier, Beth Jackson, Robin Cooper, Ernest McKenney, Suzanne Crisp, and Charles Moseley. Understanding Medicaid home and community services: A primer, 2010 edition. Washington DC: US Department of Health and Human Services and RTI International, 2010. Wolff, Jennifer, Karen Davis, Mark Leeds, Lorraine Narawa, Ian Stockwell, and Cynthia Woodcock. Family Caregivers as Paid Personal Care Attendants in Medicaid. Baltimore, MD: Johns Hopkins Bloomberg School of Public Health, 2016.

Enrollee authority: States can determine how care recipients manage their budgets, caregivers, and services:

<u>Employer authority</u> permits recipients to directly recruit and manage their service providers.
 Employer authority is <u>integral</u> to the consumer direction model. Depending on the authority, states have some flexibility to determine which employer responsibilities can be consumerdirected.

• <u>Budget authority</u> allows enrollees to manage their budgets and purchase other goods and services. States also have flexibility in determining what types of <u>goods and services</u> can be purchased under budget authority.

Enrollee supports: States are required to provide <u>supports</u> for enrollees in managing the consumer-direction process, which can include training and assistance, information about responsibilities, or access to financial management services. For example, Virginia's 1915(c) waivers include a "services facilitator" to support individuals in managing consumer-directed services.

Definition of "family:" States have discretion to determine who may provide HCBS under consumer direction. Under most authorities, states have flexibility to allow services to be provided by family members, including "legally responsible individuals" such as spouses or parents of minor children under specific circumstances. Within the 1915/c waiver, for example, states have the option to allow relatives to provide waiver services, and/or allow legally responsible individuals, such as spouses and parents of minor children, to provide personal care services. When delivering personal care-related services, the legally responsible person must be providing care that is beyond the care normally expected of a spouse or parent. In defining family for reimbursement, the state plan personal care option is the exception: legally responsible individuals may not be paid under this authority to provide personal care services.

Training and workforce requirements: State Medicaid agencies often require background checks or certification requirements for caregivers.

- States vary in the specifics of the training requirements for caregivers hired under consumer direction. Florida does not require licensing or certification to provide personal care, homemaker, or adult companion services, but does require licensure for attendant care.
- States can, through legislation, specify the types of tasks that can be delegated by a nurse to an unlicensed caregiver who receives training, as in the example of <u>Virginia's</u> regulations on nurse delegation. The AARP <u>2020 LTSS Scorecard</u> found that 26 states allow nurses to delegate at least 14 health maintenance tasks to be performed by a direct care aide, such as medication administration, respiratory care, tube feeding/gastric care, and/or bladder regimen and skin/appliance care-related tasks.

Use of representatives: Participants can choose to have a representative assist them with managing their consumer-directed services. Individuals may appoint a family member as a representative, but that family member cannot be paid to be the participant's representative, or provide paid care to the participant. (Note: Due to the COVID-19 emergency, emergency flexibilities may allow states to waive certain requirements during the public health emergency. For example, West Virginia's Appendix K for its 1915[c] waivers allows legal representatives to receive payment for certain personal care-related services under specific circumstances during the emergency.)

Three State Approaches

States can structure consumer-directed program options in a variety of ways, reflecting the needs of their residents. After a nationwide scan of Medicaid waivers and state plan options for older adults and adults with physical disabilities, the National Academy for State Health Policy (NASHP) identified three states — Connecticut, Florida, and Virginia — that have long-standing consumer-directed care programs and illustrate the various policy strategies available to states to help Medicaid enrollees (and their family caregivers) who are older adults or have physical disabilities live in their communities.

Connecticut

Connecticut's 1915(k) Community First Choice (CFC) State Plan Amendment was approved in 2015. Enrollees in Connecticut's CFC option may hire, supervise, and train their own staff and manage their budgets themselves or with support of an individual other than a spouse or legally liable individual.

Enrollees create job descriptions. Participants who choose to hire an attendant can request a pay rate subject to approval of the state. They can offer a particular wage if they believe the job description merits it (e.g., special skills, fluency in a particular language, etc.). In its 1915(k) SPA, Connecticut recommends that attendants, "be at least 16 years of age; have experience providing personal care; [be able to] follow written or verbal instructions given by the individual or the individual's representative or designee; be physically able to perform the services required; and be able



- Medicaid authority: 1915(k) Community First Choice (CFC) state plan option
- **Services:** Attendant care, transitional services, home-delivered meals, environmental accessibility adaptations, assistive technology, and voluntary training on how to hire/manage/dismiss staff
- Family caregivers: Enrollees in the CFC option can hire family members or other individuals as long as they meet qualification requirements.

 (Excludes spouses and legally responsible individuals, health care representatives, conservators, or guardians.) Caregivers may live in the home.

to receive and follow instructions given by the individual or the individual's representative or designee." Connecticut provides access to additional employee training opportunities, such as coordinating with a community college to provide personal attendant training certification or certified nursing assistant (CNA) training for personal care assistants (PCAs).

The Medicaid enrollee is considered the employer. The state's Division of Health Services (DHS) establishes the budget and determines how much of the budget can be spent each month. If participants continually exceed their budget, they may lose access to the option, and DHS also tracks underutilization. While DHS does not specifically track the use of paid family personal care providers, a state official estimates that approximately 30 percent of the roughly 4,000 individuals who use the service engage family caregivers as PCAs. Connecticut's CFC option can include older adults and people with physical disabilities, and Medicaid enrollees who require institutional levels of care are eligible.

Monitoring for fraud and abuse. Connecticut's Quality Assurance unit examines referrals and has systems and controls in place to examine and flag PCA hours. One example of a system control is related to the state's policy that disallows PCA services while a member is hospitalized. To disallow payments to PCAs submitting claims during their employer's hospitalization, Connecticut's Medicaid Management Information System (MMIS) compares PCA claims for the enrollee to hospital claims for the enrollee. If there is a hospital claim on the same day as a PCA's claim, the PCA claim is not paid. In addition, the fiscal intermediary monitors for fraud and abuse. The state also established a fraud and abuse hotline and online reporting capacity to encourage public reporting.

Reimbursement. Connecticut established a universal assessment to evaluate levels of care for all Medicaid enrollees with HCBS needs in 2015, at the same time as the CFC option was being developed. Data from this universal needs assessment has been used since then to determine tiered budget groupings within the CFC option as well. Because CFC budgets are driven by the universal assessment — as are its other HCBS programs — a Connecticut state official reported costs did not differ greatly across programs. The state is in the process of working with consultants, including the University of Connecticut, to review the tool and the data collected from the universal assessment and to revise the current budget groupings.

Payment. The fiscal intermediary pays the PCA, then submits claims for reimbursement through the Medicaid Management Information System (MMIS). The state sends information about individual budgets to the fiscal intermediary. If enrollees want to pay their PCAs a different payment rate than listed in their individual budgets, they must submit documents about how risk would be managed. This is because individual budgets are based on needed hours at the minimum wage rate. While it is permissible for participants to request higher wages, this decision decreases the number of hours available within the budget. In 2020, Connecticut selected Allied Community Resources as its fiscal intermediary through a request for proposals. The provider fee schedule is posted at ctdssmap.com. As of 2020, PCAs in Connecticut are unionized and their minimum payment rate has increased. Some program costs also have increased accordingly.

Florida

In <u>Florida</u>'s participant-directed option (PDO), the managed care plan sets the fee schedule and makes payments. The PDO, which is provided by Florida's Statewide Medicaid Managed Long-Term Care program, can serve both older adults and people with physical disabilities. The enrollee has responsibility for finding, training, and managing workers, setting hours, reporting fraud or abuse, and submitting timesheets to the managed care plan, among other responsibilities.

The PDO initially began as a consumer direction pilot in 2000 administered by the state's Agency for Health Care Administration (AHCA) and the Department of Elder Affairs (DOEA). In 2013, the participant-directed option was transitioned into the Statewide Medicaid Managed Care Long-Term Care (SMMC-LTC) program. Eight managed care plans offer PDOs.

As of June 2020, slightly more than 119,000 enrollees were enrolled in the SMMC-LTC program overall. According to state data, out of 51,848 HCBS enrollees, 7,841 were participating in the PDO as of June 2020.

Specific family caregiver hiring information is not reported in the care plan, although all care is documented in the care plan, including whether services are administered through the PDO or traditional options. Because the PDO offers flexibility in hiring caregivers, the option can be used by enrollees who desire culturally competent caregivers, or who are not satisfied with other available options. Legally responsible individuals, including spouses, can receive reimbursement. In 2020, Florida included a caregiver training benefit as part of its LTC Waiver. Training is available based on a caregiver assessment administered through the managed care plan. Each managed care plan has its own training program. This caregiver training support can be utilized only for unpaid caregivers, however.



- Medicaid authority: Statewide Medicaid Managed Care Long-Term Care (LTC) 1915(b)/(c) waiver, which includes a participant-directed option (PDO)
- Services: Allows five services through PDO: adult companion, homemaker, attendant care, intermittent and skilled nursing, and personal care services
- Family caregivers: Legally responsible individuals, including spouses, can provide PDO services as long as the caregiver is qualified, has executed a PDO work agreement, and has passed the necessary background checks; the enrollee can live in their own home or in a family member's home.

Monitoring for fraud and abuse. The Agency for Health Care Administration (AHCA), Florida's Medicaid agency, monitors for fraud and waste through the state's contracted Medicaid managed care plans, which are required to provide fiscal/employer agent (F/EA) services. The managed care plan either operates as a F/EA, or subcontracts to an F/EA vendor. The managed care plan is responsible for fulfilling certain F/EA-related tasks, including reporting of underutilization to participants/case managers, and following up with timesheet issues. AHCA conducts a desk review every quarter, which involves an audit process for compliance.

Reimbursement. Each plan has a designated fee schedule, and there are no caps from AHCA on the number of PDO hours that can be received by an enrollee, which is determined by medical necessity. Managed care plans or their vendors who serve as F/EAs provide payroll and tax management services for participants and are responsible for processing and payment of all applicable taxes on behalf of participants and their workers.

Virginia

Virginia's consumer-directed option began in the mid-1990s and was available only to individuals with physical disabilities. Virginia's options expanded over time to include individuals with cognitive impairment, and additional services, such as companion services and respite. These consumer-directed program services have since been incorporated into Virginia's HCBS waivers. Consumer direction for older adults and people with physical disabilities is part of the Commonwealth Coordinated Care Plus (CCC Plus) program operated under a 1915(b)/(c) waiver. Enrollees selecting consumer direction are provided with a list of "services facilitators" as



- Medicaid authority: Commonwealth Coordinated Care Plus 1915(b)/(c) waiver program
- Services: Participants have the option to selfdirect personal care and respite services
- Family caregivers: As of 2020, relatives other than spouses or parents of minor children can be reimbursed for services, however, during the pandemic, spouses and parents of minor children can be reimbursed for care.

part of the screening process for level-of-care eligibility assessment (administered by local Virginia Department of Health nurses and physicians or local departments of social services' family services specialists).

Services facilitators are Medicaid-enrolled providers who support participants in managing their consumer directed services. Services facilitators can:

- Assess a participant for particular consumer-directed services;
- Help develop a plan of care; and
- Provide training and support to the participant in performing their role as employer.

Participants can select workers and are considered the employer, but do not have decision-making authority over the budget. Within CCC Plus, a legally responsible relative can serve as the participant's representative and be the employer if the participant is not independently able to self-direct care, but this relative cannot also be a services facilitator, paid caregiver, or attendant. Spouses and parents of children cannot be paid to provide personal care services, but other relatives can be paid under specific circumstances. Currently, flexibilities instituted due to COVID-19 under Virginia's Appendix K waiver allow spouses and parents of children to provide services during the public health emergency.

Consumer direction is available for members living in their own homes or in family members' homes. An estimated 40 percent of caregivers are family members, according to key informant estimates.

Monitoring for fraud and abuse. Payments to family caregivers under the CCC Plus program are monitored through the Quality Management review process in the Department of Medical Assistance Services (DMAS) using the same processes used to monitor other home-based and personal care services. However, if payments are made to a family member living in the same home as the participant, the member must provide documentation to justify hiring the relative who lives in the same home as an "option of last resort." There are no limits that are specific to relatives on the number of hours of services that can be furnished.

Reimbursement. Participants in Virginia's consumer-directed option must use a fiscal/employer agent, who conducts payroll functions on the participant's behalf, including payment and withholding. DMAS issued a request for proposals to select the state's fiscal/employer agent. The fiscal/employer agent must also process background checks. Managed care organizations in CCC Plus contract with a fiscal/employer agent, and follow the same processes as the state for consumer-direction. In the 2020 budget, a 5 percent increase beginning July 2020 and a 2 percent increase beginning in July 2021 to the salary rate for attendants was approved. Time and a-half payment up to 16 hours was also approved for attendants working over 40 hours per week providing Medicaid consumer-directed personal assistance, respite, and companion services.

Lessons Learned

State policy leaders interviewed for this report all expressed value for program flexibility and choice for enrollees receiving care. They also noted the broader state goals of providing homeand community-based services alternatives over institutional services as a critical factor in supporting self-direction for people requiring institutional levels of care, and paying family caregivers. Across the highlighted states, additional themes emerged:

- Consumer direction provides an important opportunity to support health equity and culturally competent care. By giving enrollees flexibility to select caregivers and employ family members, states enhanced their ability to support the needs of underserved populations. Both Florida and Connecticut officials highlighted that the consumer-directed option allowed participants to hire caregivers who met their cultural and linguistic needs. Connecticut's Community First Choice state plan option allows enrollees, as the hiring employer, to develop job descriptions that can include speaking a specific language or possessing a particular type of certification.
- Paying family caregivers can be a cost-neutral Medicaid rebalancing strategy. States can set comparable (or lower) rates for family caregivers, manage service utilization, and support more individuals in home and community settings. Connecticut state health officials anticipated a shift from institutional care toward community-based services through use of its Community First Choice (CFC) option, and results are tracking accurately to the state's initial estimates. Connecticut also reports a lower dependence on home health agencies. Utilization of Connecticut's CFC program has grown since 2015, but a state official noted significant savings in other services. The CFC option also benefits from a 6 percent enhanced federal match. A state official in Florida also noted that the state PDO's lower service costs make the program competitive when compared to r services provided by a traditional vendor.

- Outreach to Medicaid enrollees is critical. States noted that the complexity of these programs can be a challenge to enrollment, particularly among participants who are uncertain about whether they would be required to manage their own budgets. Due to the COVID-19 pandemic and interest in avoiding facility-based care, states may have a heightened opportunity to raise awareness about consumer-directed options for personal care-related services.
- States may want to consider enhancing data collection to better identify family caregivers who are reimbursed through consumer-directed programs. States do not currently track whether enrollees in consumer-directed programs hire family members. States can consider tracking data on family caregivers within consumerdirected options to better understand the fiscal and health impact of incorporating family caregivers within these programs. Virginia officials are interested in developing mechanisms to encourage individuals who provide care to identify themselves as family caregivers. States could also support data collection to better analyze whether services are reaching at-risk populations and to better support underserved populations, including caregivers of different ethnic or racial backgrounds.
- States have a number of strategies they can use to prevent fraud and abuse. A 2017 GAO report notes that personal care services are particularly prone to incomplete data, overbilling, and risk of neglect for vulnerable enrollees. States can incorporate a range of policies that can mitigate the risk of fraud while improving the quality of care, such as:
 - o Criminal background checks;
 - o Service provider requirements and training; and
 - o Use of care managers.

States can also leverage electronic visit verification (EVV) technology (mandated by the 21st Century Cures Act for personal care and home-based services) to mitigate fraud and abuse. Anticipating the <u>particular needs of consumer-directed enrollees</u> and family caregivers can help. Also, flexible scheduling, user-friendly technology, and active engagement of stakeholders in implementation can avoid challenges. Florida noted that some MCOs provide tablets to family caregivers to utilize for EVV.

Effects of COVID-19

Enrollment support for consumerdirected programs in the three states has increased as reliance on family caregivers grew during the pandemic:

- Within a week of declaring the emergency, Connecticut permitted expedited enrollment so enrollees could hire family caregivers, and the state also allowed overtime.
 Connecticut has commissioned a report from the University of Connecticut to examine the impact of COVID-19 on LTSS.
- Florida encouraged enrollment in its PDO to obtain or provide care during COVID-19, and the state has since documented an increase in new enrollees. State administrators report they are not concerned about sustaining their managed care PDO option because the option is costeffective.
- Virginia officials noted that family members have been designating themselves as live-in caregivers in response to COVID-19. Virginia used CARES Act funding to provide personal protective equipment (PPE) to caregivers and advocate in particular for caregivers of color. CARES Act funding was also used to provide COVID-19-related hazard pay to consumer-directed caregivers who worked during the first few months of the pandemic.

• Understand how employment and scope-of-practice laws can affect family caregivers receiving reimbursement through a consumer-directed option. Family caregivers can be considered employees and subject to a range of state and federal regulations that can impact state Medicaid programs. When the US Department of Labor issued a Final Rule regarding the Fair Labor Standards Act (FLSA) that live-in caregivers for specific services could be included in receiving overtime, Florida noted that overtime hour claims increased. Plans subsequently required use of in-network providers for service hours over 40 hours per week. While Virginia's program focuses on caregivers who do not provide services that licensed or certified professionals provide, Virginia's Nurse Practice Act has been amended to allow a nurse to delegate authority to caregivers to render certain tasks without violation of licensing regulations under specific circumstances.

Conclusion

The COVID-19 pandemic is reinvigorating long-standing state efforts to support older adults and others with LTSS needs while reducing reliance on congregate settings of care. Reimbursing family members to provide some services can help states rebalance long-term care toward more home- and-community-based options and promote more person-centered long-term care, especially for underserved populations. These considerations are particularly important as states consider winding down various program changes put in place in response to the pandemic. As policymakers consider ways to support enrollees while balancing financial considerations, robust consumer-directed options that engage family caregivers can provide important and person-centered strategies for long-term care.

About This Project

Across the nation, state health programs depend on caregivers who provide critical support to help relatives, friends, and neighbors age in place while contributing significant amounts of unpaid health care services each year. To better support family caregivers, Congress passed the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act in 2018, which established the Family Caregiving Advisory Council tasked with creating the country's first national Family Caregiver Strategy.

To support the council's work, NASHP has created the RAISE Act Family Caregiver Resource and Dissemination Center in collaboration with the U.S. Administration for Community Living with support from The John A. Hartford Foundation to:

- Develop family caregiving resources for state and federal policymakers and other stakeholders;
- Provide support to the council and its subcommittee member as they craft policy recommendations;
- Convene experts and thought leaders to provide perspectives and expertise to the council; and
- Support states as they develop policies to address family caregiver issues.

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