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California's Assisted Living Waiver: An Equity Analysis

INTRODUCTION

Medi-Cal-funded home and community-based services (HCBS) are essential for the ability of California's older adults with low income and adults with disabilities to age in the community. But, as in health care generally, HCBS programs are impacted by systemic racism, discrimination, and bias that ultimately lead to disparities in health outcomes and quality of life for older adults and people with disabilities.[1] Policies and program rules that appear to be neutral can perpetuate existing inequities or result in unanticipated ones due to longstanding discrimination in health care and society more broadly. Such inequities can appear as disparities in access to these programs as well as in the quality of the services themselves.

The Assisted Living Waiver (ALW) is one of California's HCBS programs, providing comprehensive services for people living in licensed board and care residential facilities and publicly subsidized housing situated in fifteen participating waiver counties.[2] Disparities are evident in the ALW program, which enrolls a disproportionately high number of white participants and a disproportionately low number of Hispanic and Asian individuals, compared to Medi-Cal's older adult participants and those with disabilities.[3] California's Department of Health Care Services (DHCS), has started the public process to renew the ALW and subsequently integrate it with another HCBS program, the Home and Community-Based Alternatives (HCBA) waiver.[4] Because HCBA is a statewide program, the integration would also expand ALW services statewide. The renewal and integration processes create an opportunity for the state to address racial and other inequities in the current waiver by embedding an equity focus in the new integrated program from the outset.

The aim of this paper is to contribute to the renewal and integration process by utilizing Justice in Aging's Equity Framework for Evaluating California's Medi-Cal Home and Community-Based Services for Older Adults and People with Disabilities to evaluate the ALW's current program rules and policies. The paper assesses the waiver's

design and implementation using the HCBS Equity Framework's five domains: 1) Program Design; 2) Provider Availability; 3) Program Awareness and Enrollment; 4) Assessments and Authorization of Services; 5) and Provision of ALW services. For each domain, the paper provides examples of policies, program rules, and decision points in the ALW that may give rise to inequities, and suggestions for alternative formulations that could encourage more equitable outcomes.

This evaluation is not meant to be exhaustive, but instead provides a starting point to assess how California can embed equity in the new integrated waiver to ensure all eligible individuals have access to quality assisted living services. This analysis can serve as a model for conducting a similar equity assessment of California's other home and community-based programs, including the HCBA Waiver, to identify disparities that can be addressed through policy change.

HCBS EQUITY FRAMEWORK

The systemic drivers of health inequities—racism, ageism, ableism, classism, sexism, xenophobia, and homophobia—are embedded in law, policy, governance, and culture at the national, state, and local levels both in health care broadly and in HCBS. In our previous paper, An Equity Framework for Evaluating California's Home and Community-Based Services for Older Adults & People with Disabilities, we put forth an HCBS Equity Framework describing five HCBS domains in which inequities can arise: 1) Program Design; 2) Provider Availability; 3) Program Awareness and Enrollment; 4) Assessments and Authorization of Services; and 5) Provision of HCBS. The Framework calls for data collection as key to identifying and eliminating disparities within each domain.

In this paper, we use this Framework to identify possible sources of inequities in California's Assisted Living Waiver. As the ALW is integrated with the HCBA waiver, policy makers and advocates have the opportunity to improve the current waiver design by using this Equity Framework to 1) identify potential sources of inequities in the current waiver programs in order to avoid replicating them and 2) take steps to center equity at every stage of program design and implementation.

HOME AND COMMUNITY-BASED SERVICES EQUITY FRAMEWORK

PROGRAM DESIGN. In the initial design of HCBS programs, inequities can arise from policies that establish who is eligible for HCBS programs, where programs are available regionally, and what services are offered by an HCBS program.
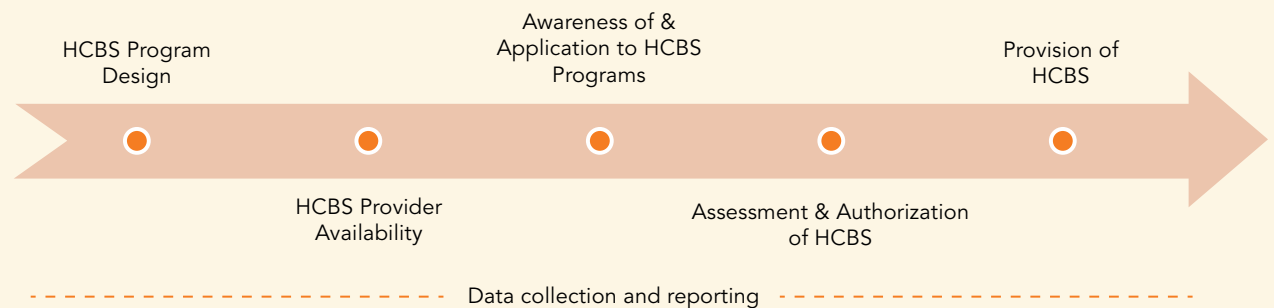
PROVIDER AVAILABILITY. Inequities in provider availability can arise from policies that dictate network adequacy, reimbursement rates, and provider investments, trainings, and supports.

AWARENESS AND ENROLLMENT IN HCBS. Inequities arise when information on program availability and eligibility requirements is not easily available and application processes are overly burdensome.

ASSESSMENT FOR/ AUTHORIZATION OF SERVICES. Implicit bias can be built into service assessment and authorization processes that can lead to inequities in who is deemed eligible.

PROVISION OF HCBS. Inequities can arise in the provision of HCBS when the unique needs and lived experience of service recipients are not built into the accessibility of services and means of measuring quality of services rendered.

HCBS Program Design

Awareness of & Application to HCBS Programs

Provision of HCBS

HCBS Provider Availability

Assessment & Authorization of HCBS

Data collection and reporting

DATA: WHO IS ACCESSING THE ALW?

Comprehensive and intersectional data collection and reporting is essential to advance equity in all health care, including at-home care.[13] In December 2022, California took an important step towards providing essential data through the release of its first-ever Long-Term Services and Supports (LTSS) Data Dashboard.[14] This dashboard publicly reports utilization and enrollment data for California's long-term care and HCBS programs categorized by race, ethnicity, language spoken, and other demographics. The dashboard currently contains some limited data about the ALW; updates and improvements to the dashboard are anticipated over time.

A preliminary examination of the ALW data reveals disparities in utilization by race among white, Hispanic, and Asian Medi-Cal enrollees. White individuals, for example, represent 24% of Medi-Cal enrollees age 65 and over or disabled, but represent 39% of those enrolled in the ALW.[15] Meanwhile, Hispanic individuals represent 31% of Medi-Cal enrollees 65 and over or disabled, but just 12% of those enrolled in the ALW, and Asian individuals make up 16% of the older or disabled Medi-Cal population but only 9% of waiver recipients (See Table 1). These initial data warrant further analysis to determine whether differences in utilization across race and ethnicity are statistically significant and whether additional disparities arise when reviewing other demographic characteristics individually or intersectionally like age, disability, sexual orientation, gender, and primary language.

California's HCBS Gap Analysis and Multi-Year Roadmap, the state's recently-launched initiative to assess gaps in the HCBS programs and networks, presents an opportunity for the state to develop and collect additional data that can bolster its ability to uncover disparities in the ALW program.[16] While current available data can track disparities in who is currently receiving services under the waiver, several other important pieces of data are missing from the dashboard that could help identify disparities in access and quality. The Gap Analysis Initiative and future iterations of the Dashboard can help provide a more complete picture by 1) using stratified data by multiple fields to analyze how different factors affect disparities in utilization; 2) comparing utilization data with the total number of Medi-Cal enrollees meeting the waiver's level of care who *could* be eligible to access ALW services, stratified by demographic groups and HCBS utilization; and 3) analyzing grievances, denials, wait times, and disenrollment data to assess program and service quality. As discussed in An Equity Framework, these measures can uncover disparities in quality across the ALW.[17]

The Assisted Living Waiver is available to individuals age 21 and older needing nursing facility level care who want to live in the community, and have enough income to pay the Supplemental Security Income/State Supplementary Payment (SSI/SSP) nonmedical room and board rate.[5] Care Coordination Agencies (CCAs) handle waiver assessments, applications, and care coordination.[6] Facilities provide services, including personal care services, housekeeping, intermittent skilled nursing care and residential habilitation.[7]

ALW participants must move into a private or semi-private room in one of two types of waiver-enrolled licensed board and care facilities—Residential Care Facilities for the Elderly and Adult Residential Facilities, located in one of 15 waiver counties.[8] Currently, 686 facilities are authorized for the ALW.[9] While cumulative capacity is approximately 27,000, only a fraction is made available for ALW use.[10] As such, 8,785 individuals are currently enrolled in the ALW and 3,626 are on the waitlist.[11] ALW services may also be available in publicly subsidized housing through home health agencies, but only eight approved publicly subsidized sites and one approved home health agency operate in all of California.[12]

TABLE 1. 2021 ALW UTILIZATION BY RACE[18]

RACE/ETHNICITY	ALL MEDI-CAL 65+ OR DISABLED ADULTS	% OF TOTAL	ALW	% TOTAL ALW USERS
AI/AN	10,072	.43	28	.39
Asian/PI	392,383	16.82	**673**	9.3
Black/AA	221,821	9.51	695	9.61
Hispanic	712,278	30.53	844	11.67
Other	170,024	7.29	326	4.5
Unknown	257,431	11	1,875	26
White	568,723	24.38	2,794	38.62
Total	2,332,735		7,235	

The disparities identified in the limited data currently published in California's LTSS Dashboard demonstrate a need for an equity-centered assessment of the ALW and ongoing oversight to ensure disparities are identified and addressed as new policies are implemented.

DOMAIN #1: PROGRAM DESIGN

Basic program design decisions, such as where services are available, how many individuals can be served, and how limited spots are allocated can give rise to inequities in waiver access.

Though in high demand, as demonstrated by its long-standing waitlists, the ALW is difficult to access in great part due to enrollment caps and geographic limitations.[19] At the beginning of the current waiver term in 2019, the number of total slots across the 15 waiver counties was limited to 5,744.[20] For comparison, an average of 78,000 Medi-Cal enrolled older adults and individuals with disabilities use long-term care facilities across California every month.[21] In 2022, the waiver was amended to add an additional 7,000 slots in order to clear the state's long waitlist. These slots are distributed monthly in limited batches to Community Care Agencies (CCAs), which administer the waiver. Since this is an ongoing process, the waitlist has not yet been cleared, and currently has approximately 3,600 individuals.[22] Prior to the recent addition of waiver slots, eligible individuals were waiting for as long as three years to get services.[23] Data is not available on how the increase in slots has impacted waiver wait times.

Limited waiver slots and long wait times for those slots have significant consequences for a medically fragile population requiring nursing facility level of care. The impact is greatest on those who do not have the means or support to continue living in the community while they wait for a slot. For example, LGBTQ+ older adults are "more likely to live alone, be socially isolated, and have less family support, disproportionately leading to a reliance on long-term care," and can be more adversely affected by policies that require help at home while waiting for additional care or support.[24] Barriers to accessing the ALW can lead to worse health outcomes and greater rates of institutionalization for older adults of color who are more likely to be economically insecure and, therefore, less likely to have the resources to get the help they need while they wait for waiver enrollment.[25]

Geographic restrictions further reduce access to the ALW program. Waiver access has been geographically limited from its inception. The waiver launched in 2005 as a demonstration pilot in only three of California's 58 counties.[26] In 2009, the ALW was authorized as a 1915(c) HCBS waiver, and increased the geographic availability of the waiver to 15 counties. However, nearly 20% of California's Medi-Cal eligible older adults and people with disabilities live outside of these 15 counties and, as a result, are unable to access the ALW.[27]

Policies that dictate how limited waiver slots are allocated to the CCAs and how waitlists are maintained may further drive inequities in who is accessing the program. For the ALW, CCAs allocate their slots to individuals on their waitlist, and DHCS uses the number of individuals a CCA is able to place in a month to inform the next month's slot allocation.[28] Waiver slot allocation is based on CCA staff capacity and the number of people on CCA waitlists, not county demographics or overall county/regional need. This structure can incentivize CCAs to assist applicants who are easier to place. Because Black, Hispanic, and Native applicants have higher rates of disabilities, including Alzheimer's and dementia, they may be disproportionately affected by this policy.[29]

Another example of where inequities can arise is in how priorities are set for who can access limited waiver slots. Under current rules, 60% of new waiver enrollments must come from institutional transitions into community settings, and 40% of new enrollments can come from community enrollees. The policy may create unintended incentives that could produce inequities in access. For example, shorter wait times for institutional transfers into waiver services may lead some CCAs to advise applicants to move into institutional care or to open Adult Protective Services cases in order to get preference on the waiver's long waitlist. Racial and disability-related inequities may arise due to implicit bias that informs decision making when CCAs exercise discretion in who to assist in jumping the waitlist, and who will experience extended wait times.

Unfortunately, limited data are available about how these policies impact who gets ALW slots and who is left on the waiting lists. ALW waitlists are administered by DHCS for each CCA.[30] The state provides no demographic data about who is on the waiting list, how long they are on the waitlist, and what portion of them are eventually enrolled in the program. This lack of transparency prevents government agencies, policy makers, and advocates from identifying disparities in access.

The table below summarizes how each program design element discussed above contributes to inequities in access to the ALW, and describes how California can avoid replicating these inequities as it integrates the ALW into the HCBA waiver.

HCBS POLICY ELEMENT: PROGRAM DESIGN	EQUITY EVALUATION	INTEGRATION OPPORTUNITIES
Capped enrollment	Limiting the number of available ALW waiver spots resulted in a long waitlist. Higher rates of economic insecurity can make it harder for older adults of color and LGBTQ+ older adults, who experience disproportionate health inequities that require enrollment in programs like the ALW to access help at home while awaiting access for this higher-level care.[31]	Removing enrollment caps in the integrated waiver, coupled with ongoing monitoring of enrollment demographics, can reduce disparities caused by long wait times, lack of access and complicated spot allocation strategies. Short of removing caps, DHCS could increase enrollment caps to meet anticipated demand for the program and minimize waitlist use.

HCBS POLICY ELEMENT: PROGRAM DESIGN	EQUITY EVALUATION	INTEGRATION OPPORTUNITIES
Geographic limitation	Limiting the waiver to 15 counties leaves individuals in non-covered regions without services. Individuals in unserved or underserved areas must move far from their communities to access ALW services, or endure without them.	The expansion of ALW services statewide is an important step to address this issue. To ensure that expansion addresses inequities, DHCS should monitor the expansion closely and collect regional and statewide data, including demographic data. The HCBS Gap Analysis initiative, currently underway, can be leveraged to identify disparities that may guide the statewide expansion.
Allocation of waiver slots and population prioritization	Waiver allocation is based on CCA capacity and waitlists, not county demographics or overall need, which is both a potential cause of disparities and a missed opportunity to target access to communities in greatest need. Current population prioritization for slots creates incentives that may also drive disparities.[32]	Waiver allocation based on county demographics and need, not CCA capacity, can help meet the needs of under-served communities. DHCS should collect and use data to determine current unmet need and prioritize certain populations for new and expanded waiver slots. Prioritization could be done with an awareness of existing racial and other disparities. California could allocate waiver slots based on quality measures and standards rather than using efficiency as the central criterion in consumer placement.
ALW waiver waitlist administration	ALW waitlists are administered by DHCS for each individual CCA. Data about who is on the waitlists is not reported publicly by the state nor are individuals able to access information about their placement.	If a waitlist is maintained, transparency, communication, and strategies for offering support during the waiting period can be used to reduce disparities. The waitlist should be monitored on an ongoing basis by collecting and publishing CCA-specific data on waitlist demographic makeup and wait times, waitlist attrition, and rates of enrollment from the list. Intersectional data should at a minimum include race, ethnicity, gender, sexual identity, spoken language, and disability.

DOMAIN #2: PROVIDER AVAILABILITY

Inequities in provider availability can arise from policies that dictate network adequacy, reimbursement rates, and provider investments, trainings, and supports.

Disparities in access to the ALW arise when there are not enough service providers—and by extension, CCAs who administer the waiver—to meet the needs of all communities. With an ongoing waitlist, there are not enough ALW providers with sufficient capacity to serve the current waiver population. Because in large sections of California there are no ALW providers or agencies, the statewide waiver expansion will require the state to expand beyond the 33 CCAs currently operating in 15 counties. But even in current waiver counties there are often too few providers. For example, in Santa Clara County, there are 67,092 older adults enrolled in Medi-Cal but only two ALW providers.[33]

Even in counties with larger numbers of providers, inequities can arise if facilities are concentrated in some communities, leaving others in the county unserved. For example, a spatial analysis of Los Angeles County's residential care providers found that in spite of having a significant share of the state's residential care facilities, within sub-regions of the county, "the number of facilities is inversely associated with the proportion of older Blacks, Hispanics, and older adults in poverty."[34] The analysis found that Hispanic older adults in particular lack access to residential care facilities.[35]

Setting clear targets, similar to those used in network adequacy standards, for ALW or HCBA provider availability in all areas of the state could help guide focused investments to address inequities in provider concentration. Investments could include an expansion of home health agencies that can service individuals in publicly subsidized housing, which predominantly serve people of color.[36] These targets should be designed to ensure that communities with the greatest need for these services have sufficient providers in their community to meet that need.

Disparities in provider access can be difficult to overcome when administrative burdens and low provider reimbursement rates create barriers to entry for new providers to participate, particularly for smaller community-based providers. Because community-based organizations provide essential services in underserved communities, particularly Black communities, processes that prevent their participation can exacerbate inequities.[37] For example, difficulty learning about a program and inaccessibility of supportive materials for application completion, documentation, and program compliance are recognized as sources of disparities in health care generally.[38] These same challenges can make it harder for community organizations with small staff, narrower skill sets, limited resources, or financial instability to navigate processes for becoming an ALW provider.[39] Low-income areas with a higher proportion of Medi-Cal enrollees are less likely to have assisted living providers and would benefit from more provider availability in their communities.[40] Robust technical assistance and clear state guidance both in the application process and for ongoing compliance with changing regulations could help smaller, less-resourced organizations provide necessary, high quality resources in under-served communities.

Finally, inequities in provider availability can also arise when reimbursement rates are too low to attract provider participation in underserved communities.[41] Reimbursement rates should be set at levels high enough to incentivize provider participation in communities that currently lack access to services.

The table on the following page summarizes how inequities in provider availability can increase disparities in access to the ALW and suggests steps California can take to improve access through the integration of the ALW into the HCBA waiver.

HCBS POLICY ELEMENT: PROVIDER AVAILABILITY	EQUITY EVALUATION	INTEGRATION OPPORTUNITIES
Provider network standards	Disparities may arise when there are no or limited ALW providers available in specific communities, inequities in the type of services available, long distances that program participants must relocate to access an ALW provider, and disparities in enrollment wait times.	DHCS could implement a network adequacy standard framework that is equity centered and informed by demographic data, which can guide future investment in program capacity and infrastructure. Building data collection and publication into the waiver can help the state assess whether sufficient waiver beds are available equitably across communities and demographic groups on an ongoing basis. This data can be used to guide investments such as the Community Care Expansion Program to build capacity and infrastructure and increase service availability in under-represented communities statewide.[42]
Administrative burden	Administrative burdens such as outdated provider manuals and opaque processes create barriers for new, smaller, and less-resourced providers from enrolling in the ALW, exacerbating inequities in access to the ALW, particularly in low-income communities of color served by smaller providers.	With the waiver integration, DHCS has an opportunity to improve and update the provider manual and the waiver's supporting guidance. The Department can also provide robust technical support and training opportunities for small organizations that may be interested in enrolling as waiver providers.
ALW provider reimbursement rates	Low reimbursement rates for ALW providers limit provider participation in the program and create disparities in which communities have access to services.	California should study its rate structure to ensure that there are sufficient providers to reach currently underserved communities.

DOMAIN #3: AWARENESS AND ENROLLMENT

Inequities arise when information on program availability and eligibility requirements is not easily available and application processes are overly burdensome.

It can be difficult for older adults to get information about the ALW because program information is not broadly available in a consumer-oriented or accessible manner. CCAs and providers report that most applicants hear about the ALW either through word-of-mouth or directly through agencies or providers that steer them to the program. Communities that are already connected to services are more likely to find out about programs promoted through word-of-mouth, whereas communities that are underserved are unlikely to be aware of program options. To ensure the ALW is accessible to all eligible populations, communication must be culturally and linguistically accessible and targeted toward underserved racially, linguistically, and ethnically diverse communities.

Because almost no consumer-facing information is available about the ALW directly from the state or counties, such as through the DHCS website or county offices, communication to potential applicants and enrollees about the ALW is exclusively delegated to the CCAs.[43] These agencies use their discretion on where to invest outreach and communication efforts. The lack of state monitoring or guidance can mean that organizations may not make the investments, such as culturally relevant promotional materials and language services, to reach new and underserved populations. Implicit and explicit biases may also result in less outreach or offering of services to applicants with dementia and other complex conditions that disproportionately impact marginalized communities.

Disparities related to outreach and communication efforts could be mitigated with state guidance to the CCAs about how information about services can best be communicated, how to reach underserved communities, and how to make outreach efforts linguistically and culturally accessible. The state should also track data to ensure such efforts are effective in bringing a diverse pool of applicants into the program. Implicit bias training provided to all CCAs and their staff can raise awareness and provide corrective strategies.

Knowing a program exists is just the first step towards gaining access to that program. Inequities can also arise when application processes are unclear, complex, or not provided in applicants' languages. Research has demonstrated that application processes that are overly burdensome or complex disproportionately impact people of color.[44] The ALW application process is complex, requiring a multi-step assessment, and can only be done with the CCA's assistance. There is no way for the individual to apply on behalf of themselves and, as discussed above, there is no way for the individual to learn about the program except for through the CCA.

The process is even more difficult for people with limited English proficiency because nearly all the ALW forms and assessment tools are in English only. DHCS could identify opportunities to simplify the application process. Translating all program materials into Medi-Cal's threshold languages, and compliance with and enforcement of federal and state legal regulations requiring the use of language interpretation services to communicate with individuals with limited English proficiency can also remove barriers and promote access to the waiver.

The table on the following page summarizes how lack of awareness about the ALW program and complexities in the enrollment process can lead to disparities and provides recommendations California can take to improve access for all as it integrates the ALW into the HCBA waiver.

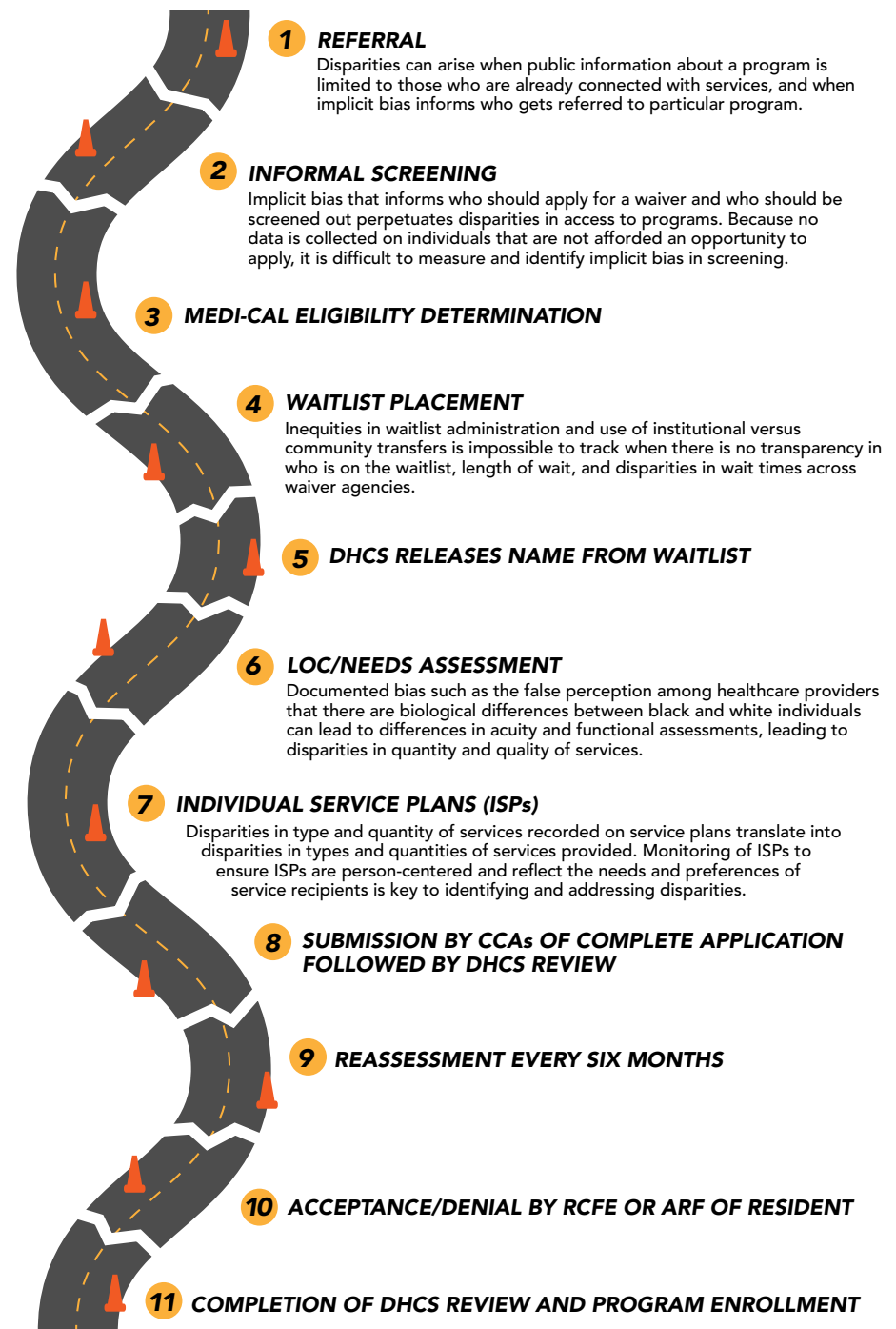| HCBS POLICY ELEMENT: AWARENESS OF AND ENROLLMENT IN HCBS PROGRAMS	EQUITY EVALUATION	INTEGRATION OPPORTUNITIES
DHCS communication	Limited consumer-directed information on the waiver creates a barrier preventing potentially eligible individuals from applying and may bias access to the program in favor of those communities that are already connected with services or waiver agencies. The information that DHCS does publish is inaccessible to non-English speakers, individuals with limited English proficiency, and individuals with visual impairments.	The state could devise an accessible, equity-centered communication strategy to inform potentially eligible individuals of the ALW, and how to access it. The strategy should include developing high-quality, consumer-friendly outreach materials translated into Medi-Cal's threshold languages.[45] An accessible, culturally competent website with comprehensive program information and targeted outreach channels are key to ensuring that the program is accessible. In-person and non-web outreach efforts through trusted community-based channels, beyond just waiver providers and CCAs, should be a central part of any communication campaign to ensure comprehensive reach.[46]
Community outreach communications and resources	Current outreach, which relies on word-of-mouth and CCAs to identify potential applicants, limits ALW access to communities that are already connected to services. Implicit and explicit biases can influence CCA decisions about who to inform about the waiver and what outreach to undertake, which can perpetuate racial and other disparities. Without intentional outreach to diverse communities, disparities in ALW access are likely to persist.	To ensure program awareness is equitable across communities, DHCS should issue clear guidelines to CCAs requiring outreach plans to include strategies to reach racially and ethnically diverse communities and other underserved communities. DHCS should also implement monitoring measures, such as outreach plan audits and data collection, to track disparities in program applications. DHCS should also require bias training for all participating CCAs.
ALW application process	The ALW application process is complex, and application completion and submission require the assistance of a CCA. As discussed above, implicit bias can drive disparities in who gains access to the application process.	DHCS should implement a universal application process for all of California's HCBS programs. This would separate the application process from needs assessments, simplifying the application process and reducing the likelihood that implicit bias rather than eligibility determines who applies. Empowering applicants to initiate applications can help reduce disparities in who applies and who is screened out, and promote consumer choice.

DOMAIN #4: ASSESSMENT AND AUTHORIZATION OF SERVICES

Implicit bias can influence service assessment and authorization processes that can lead to inequities in who is deemed eligible for services.

The ALW eligibility process is divided into three key stages that applicants need to progress through prior to a formal application: informal screening, level-of-care determination, and needs assessment. Each stage creates opportunities for bias that may prevent potential participants from accessing ALW services.

Informal and inconsistent screening of potential applicants prevent potentially eligible individuals from applying for the ALW program. Different CCAs may create their own discretionary screening processes that can keep potentially eligible individuals from being formally evaluated for the ALW through the program's own assessment tools.[47] Screening is not a formal part of the process but may be used by CCAs to make decisions about who, for example, is a good fit for the waiver. There is no definition for what a good fit is, leaving it up to each CCA to determine whether an individual proceeds with the application process based on subjective criteria. Because screening occurs prior to the state's application process, it lacks transparency and state oversight. These informal practices are prone to implicit bias—racial, ethnic, ableist, sexist or homophobic bias—which can all influence this type of discretionary decision-making about who might be well-suited for referral and enrollment in an HCBS program, and can play a significant role in who is informed about programs or services that may be available to them in the first place. For those who pass through the initial screening stage, bias in both the assessor and the formal assessment tool itself can influence key parts of the eligibility process (nursing facility level-of-care determination and care needs assessment), which can also contribute to disparities.

THE WINDING PATH TO ALW ENROLLMENT

1 REFERRAL
Disparities can arise when public information about a program is limited to those who are already connected with services, and when implicit bias informs who gets referred to particular program.

2 INFORMAL SCREENING
Implicit bias that informs who should apply for a waiver and who should be screened out perpetuates disparities in access to programs. Because no data is collected on individuals that are not afforded an opportunity to apply, it is difficult to measure and identify implicit bias in screening.

3 MEDI-CAL ELIGIBILITY DETERMINATION

4 WAITLIST PLACEMENT
Inequities in waitlist administration and use of institutional versus community transfers is impossible to track when there is no transparency in who is on the waitlist, length of wait, and disparities in wait times across waiver agencies.

5 DHCS RELEASES NAME FROM WAITLIST

6 LOC/NEEDS ASSESSMENT
Documented bias such as the false perception among healthcare providers that there are biological differences between black and white individuals can lead to differences in acuity and functional assessments, leading to disparities in quantity and quality of services.

7 INDIVIDUAL SERVICE PLANS (ISPs)
Disparities in type and quantity of services recorded on service plans translate into disparities in types and quantities of services provided. Monitoring of ISPs to ensure ISPs are person-centered and reflect the needs and preferences of service recipients is key to identifying and addressing disparities.

8 SUBMISSION BY CCAs OF COMPLETE APPLICATION FOLLOWED BY DHCS REVIEW

9 REASSESSMENT EVERY SIX MONTHS

10 ACCEPTANCE/DENIAL BY RCFE OR ARF OF RESIDENT

11 COMPLETION OF DHCS REVIEW AND PROGRAM ENROLLMENT

Because all three of these assessments occur prior to the application submission, potential applicants have no recourse to appeal screening and assessment decisions. Creating a path to appeal would provide recourse to individuals who are kept out of the program by these preliminary decisions. While data collection, periodic review of assessment tools for bias, and implicit bias training can help monitor, identify, and address disparities in assessment processes, DHCS should establish a right to due process at this early phase of the application process to address potential discriminatory barriers to access.

The table below identifies areas where program assessments and authorization may drive disparities, and ways to address them in the waiver integration.

HCBS POLICY ELEMENT: ASSESSMENT AND AUTHORIZATION	EQUITY EVALUATION	INTEGRATION OPPORTUNITY
ALW informal screening	Some CCAs use screening processes to assess client readiness for moving into a Residential Care Facility for Elderly (RCFE), safety issues, or likelihood of enrollment. Implicit bias can influence the outcome of screening processes, inequitably diverting certain groups from programs they are otherwise entitled to participate in.	The state could create a universal HCBS application for all LTSS applicants to ensure potential eligible applicants are identified and ensure that all steps in the application process are appealable. As an alternative, DHCS could standardize ALW screening processes and require CCAs to collect and report data to DHCS for all screened applicants in order to identify disparities in waiver access.
ALW "level of care" determination	Level of Care determinations are made using a state-provided tool that is integrated with the needs assessment. Inequities can occur when determining who meets program-required level of care.	DHCS should conduct ongoing data collection and monitor disparities in the level of care determinations in approved and denied waiver applications. Bias training can help mitigate implicit bias in assessment administrators.
ALW needs assessment tool	The state assessment tool used to determine the types and frequency of services provided can create disparities when bias in the administration of the tool or the tool itself prevents the results from accurately reflecting participant need.	State assessment tools should be routinely tested for bias. Data tracking of types and frequency of services stratified with demographic information can help identify inequities in assessment administration and interpretation. Bias training can help mitigate disparities due to bias in the assessor.

DOMAIN #5: PROVISION OF SERVICES

Inequities can arise in the provision of HCBS when the unique needs and lived experiences of service recipients are not built into the accessibility of services and means of measuring quality of services rendered.

" Equitable care is **when quality does not vary because of personal characteristics such as gender, race, ethnicity, geographic location, and socioeconomic status**.[48]

Disparities in assessments can lead to disparities in provision of services, including the type, quality, and quantity of services offered to waiver enrollees. In the ALW context, disparities in provision of services can arise during the drafting of the Individual Service Plan (ISP) and during the provision of the services themselves. Even when service plans are equitably drafted, implicit bias, language barriers, and lack of cultural sensitivity can perpetuate disparities in the type, amount, and quality of services delivered. Meaningful quality measures that assess and report disparities in provision of services are key to identifying and addressing these inequities.

Inequities embedded in ISPs, which identify participant needs and how they are to be met, can drive inequities in the types of services provided. Just as a doctor's bias can result in improper pain assessment and treatment, the ISP drafter's racial, or other, bias can result in a plan that inadequately reflects the needs, preferences, and experiences of the participant.[49]

Disparities can also arise when services recorded in the ISP are not actually provided, or are provided at a lower level than the ISP indicates or than what the recipient requires. Finally, disparities can also occur when services are not provided in a culturally appropriate manner in the language preferred by the participant.

Inequities in service delivery cannot be identified and addressed without meaningful quality measures that adequately assess disparities in the services rendered or if they do not include the collection and reporting of demographic data. Monitoring of disparities in both the creation and implementation of the ISP are key for ensuring that all waiver participants are provided quality, person-centered care. Equitable access to high-quality services requires on-going monitoring.

Unfortunately, the quality measures currently included in the ALW do not measure qualitative aspects of the waiver, instead focusing solely on administrative data. For example, level-of-care determinations are monitored not by the quality or accuracy of the determination, but by the percentage of waiver enrollees for which CCAs actually performed initial level-of-care determinations.[50] Because all enrollees must have a level of care determination as a condition for DHCS application approval, this is not a meaningful measure of quality. The state needs to develop a robust system of quality measurement for ALW providers.

To identify disparities in service quality, the state also needs a mechanism to receive, record, and track user experience through, for example, grievance procedures and user surveys. Disparities in user experience are particularly important to track given the intimate nature of care services provided under the waiver, and the vulnerabilities this intimacy creates for recipients. LGBTQ+ individuals, for example, are particularly vulnerable to ongoing discrimination in their daily care. "Misgendering, including harassing and willful use of incorrect pronouns is a particular issue for individuals relying on care in residential settings."[51] While the ALW lists grievances as a data point in quality assessments, DHCS has not yet created a mechanism for receiving and recording consumer grievances about the ALW, nor has it created a formal procedure for responding to them.[52] Without a formal opportunity to raise grievances and seek redress, typically it is the more resourced individuals who are able to advocate for—and receive—higher quality services.

This table below shows the areas of the ALW program that can cause inequities in service provision, and steps California can take to reduce disparities through the waiver integration.

HCBS POLICY ELEMENT: SERVICE PROVISION	EQUITY EVALUATION	INTEGRATION OPPORTUNITIES
Individual Service Plans (ISPs)	Disparities can occur when service plans are not truly individualized, and understate or do not reflect the needs of the care recipient. People with limited English proficiency are at particular risk of poor ISP quality if service planning is not conducted in the recipient's primary language. Disparities also arise when recipients do not receive the care outlined in the plan or the care provided is low quality.	DHCS could provide guidance on drafting culturally and linguistically appropriate ISPs, assess DHCS's own forms for bias, provide grievance opportunities for recipients who feel the ISP does not reflect their needs and goals, and monitor for disparities in provision of services and in the ISPs themselves.
ALW language access services	Disparities can occur when programs and services are not provided in the language of the participant. Disparities in service quality and access can also occur when ALW agencies and providers fail to provide translated materials or engage interpretation services, do not provide state forms, manuals, and documents in threshold languages, and when the state fails to enforce language access protections.	DHCS can use the ALW/HCBA waiver integration as an opportunity to make all forms, communications, and manuals comply with language access requirements. The state can encourage proactive language access by requiring CCAs and providers to adopt language access plans that lay out how language needs of the potential recipients in their service area will be addressed. Finally, the state could monitor the implementation of those plans—including using "secret shoppers" and participant surveys—and create an enforcement strategy to ensure compliance.
Cultural competence and humility	Limited cultural competence and bias trainings for providers are mandated by law.[53] CCAs can decide on the training program used without oversight from the state. Some programs create their own in-house training while others hire a third-party trainer.	DHCS should expand its current requirement that facilities undergo LGBTQ+ training to encompass other anti-bias and cultural competency issues. Training could include programs such as SageCare that focus on cultural competency in working with specific populations.[54]
Grievance procedures and quality measures	The ALW currently lacks effective quality measures.	DHCS could track disparities in hours of care delivered, incidence of hospitalization, program discharge, injury and death, staff-to-resident ratios, user experience, grievances and resolutions, and other measures that may reflect a relationship between care delivery and health outcomes. DHCS could also consider implementing accountability measures to ensure that quality issues are addressed consistently across all populations.[55]

CONCLUSION

California's Assisted Living Waiver has the potential to be a key part of the state's continuity of care for older adults and people with disabilities needing HCBS but could be even more effective if designed to address existing inequities. Unfortunately, the waiver program is vulnerable to disparities in who can access the program due to policy decisions ranging from geographic limitations and enrollment caps, to complex administrative structure, lengthy waitlist delays and complex application and waitlist processes, to potential bias in assessments and provision of services, and more. Historically, the lack of publicly available program data means that equity-centered oversight has been largely absent. California's HCBS Gap Analysis and Roadmap initiative is an opportunity for the state to identify unmet needs and disparities in the waiver program, and begin to address these disparities by making equity a central focus in the HCBA-ALW Integration. An equity-centered evaluation of the ALW's program rules and policies can help the state address inequities in the current ALW, while affirmatively embedding equity in the new integrated program.

ENDNOTES

1   Christ, Amber and Dickman, Hagar, "Equity Framework for California's HCBS Programs," (December 2022); see also UCLA Center for Health Policy Research, "Demand for Aging and Disability Services Is Increasing in California: Can We Meet the Need?," (Nov. 2022).

2   See DHCS, "Assisted Living Waiver." For more on California's home and community-based programs, see DHCS, "Medi-Cal Waivers."

3   See Table 1, citing DHCS, LTSS Data Dashboard, 2021 enrollment numbers.

4   The HCBA Waiver provides care management and coordination of long-term care and support services through a variety of state HCBS programs to individuals in their home, and is accessible to both children and adults. See DHCS, "Home and Community-Based Alternatives Waiver," (2/28/2023). As part of the HCBA and ALW integration process, DHCS convened a stakeholder group which includes 15 CCAs, five waiver providers, a managed care plan representative, three industry associations, five consumer advocate organizations, and two participant family members. DHCS, "Home and Community-Based Alternatives Waiver and Assisted Living Waiver Integration" (8/8/2022).

5   DHCS, Medi-Cal Eligibility Procedures Manual, Article 19 (1997). Revised by Medi-Cal Eligibility Procedures Manual Letter No. 307 (Dec. 10, 2009).

6   DHCS, ALW Renewal 2019-2024 (February 25, 2019).

7   *Id.*

8   *Id.*

9   DHCS, Assisted Living Waiver (ALW) Program Participating Facilities, (current as of 3/10/2023).

10 *Id.*

11 ALW Year-to-Date Dashboard, January 2019-January 2023 (March, 2023).

12 DHCS, ALW Renewal 2019-2024.

13 Christ, Amber and Huyenh-Cho, Tiffany, "Using Data for Good: Toward More Equitable Home and Community-Based Services in California's Medi-Cal," (Dec. 2021).

14 DHCS Data Dashboard Initiative.

15 DHCS, LTSS Data Dashboard, 2021 enrollment numbers.

16 California is currently conducting a Gap Analysis and Multi-Year Roadmap with the goal of assessing the gaps in the HCBS programs and networks. DHCS Gap Analysis and Multi-Year Road Map (Last visited on March 10, 2023).

17 Christ, Amber and Dickman, Hagar, "Equity Framework for California's HCBS Programs," at 13.

18 It is noteworthy that the number of individuals whose race or ethnicity is unknown makes up over 10% of the total number of enrolled older adults and adults with disabilities. Demographic information is essential for identifying and addressing inequities. Improving the accuracy of demographic identification not only for race but also for sexual orientation or gender identification will require state investment in strategies that both respect privacy rights of respondents and incentivize higher response rates.

19 ALW Year-to-Date Dashboard, January 2019-January 2023 (March, 2023).

20 *Id., see also* DHCS, ALW Renewal 2019-2024 (February 25, 2019) at 25; DHCS, ALW Amendment, (July 1, 2021).

21 DHCS, LTSS Data Dashboard, 2021 enrollment numbers. See also DHCS, Medi-Cal at a Glance, (November 2022), reporting approximately 42,000 LTC users who are enrolled in an LTC aid code. We use the LTSS Dashboard count because it includes long-term care use regardless of aid code enrollment, and accounts for short, medium- and long-term facility stays.

22 ALW Year-to-Date Dashboard, January 2019-January 2023 (March, 2023).

23 Cal Matters, "Operating Under Water: Families Trying to Place Loved Ones in Medi-Cal Assisted Living Program Wait Years," (Sep. 7, 2022).

24 Sage, "LGBTQ+ Older Adults Fear Discrimination in Long Term Care, Need Protection," (Aug. 16, 2021).

25   Mutchler, Jan, Li, Yang and Roldan Nidya Velasco, Caring Across Generations, "Precarious Aging: The Spatial Context of Racial and Ethnic Disparities in Economic Security" (2020) (Economic insecurity occurs when "necessary expenses for housing, food healthcare and other essentials exceed the economic resources available to pay for them.").

26   Cal.Welf. & Inst.Code § 14132.26; DHCS, "Assisted Living Waiver RCFE Provider Handbook,(2009) at 4; CANHR, "Evaluating California's Assisted Living Waiver Program."

27   ALW is currently available in the following counties: Alameda, Contra Costa, Fresno, Kern, Los Angeles, Orange, Riverside, Sacramento, San Bernardino, San Diego, San Joaquin, San Mateo, Santa Clara, Sonoma and San Francisco Counties. DHCS, ALW Renewal 2019-2024, at 6. In 2021 there were 1,928,486 individuals 65 years or older enrolled in Medi-Cal in the fifteen counties out of 2,332,732 total in the state; out of 3,708,000 Medi-Cal enrolled individuals with a disability, 3,025,000 live in the fifteen covered counties; DHCS, LTSS Data Dashboard, last checked on 3/2/2023.

28   ALW PL #22-01

29   38% of older Black adults are living with disabilities, compared with 33% of all older adults. See Administration for Community Living, "2020 Profile of African Americans Age 65 and Older," (2021); National Institute on Aging, "Data shows racial disparities in Alzheimer's disease diagnosis between Black and white research study participants,"(Dec. 16 2021); Hispanic adults are 1.5 times as likely to have Alzheimer's and dementia than non-Hispanic whites. See Lin, Pei-Jung, Daly, Allan, Olchanski, Natalia, Cohen, Joshua, Neumann, Peter, Faul, Jessica, Fillit, Howard, Freud, Karen, "Dementia Diagnosis by Race and Ethnicity,"(Aug 1, 2021); Native individuals are 50% more likely than the general U.S. population to have a disability, see CMS, AI/AN Age and Disability, (12/01/2021).

30   ALW PL #22-01.

31   Lin, Pei-Jung, Daly, alla, Olchanski, Natalia, Cohen, Joshua, Neumann, Peter, Faul, Jessica, Fillit, Howard, Freud, Karen, "Dementia Diagnosis by Race and Ethnicity,"(Aug 1, 2021); Emlet, Charles A., "Social, Economic and Health Disparities Among LGBT Older Adults," Generations, (March 30, 2017).

32   DHCS, ALW PL #22-01 (May 3, 2022).

33   DHCS, Medi-Cal Certified Eligible, by Month of Eligibility, County, Race/Ethnicity, and Age Group. Note that 17% of Santa Clara's participants did not report demographic information, and can potentially affect demographic breakdowns.

34   Lynch, Emily E., Malcoe Lorraine Halinka, Laurent Sarah E., Richardson, Jason, Mitchell, Bruce C., Meier, Helen C.S., "The legacy of structural racism: Associations between historic redlining, current mortgage lending and health," Population Health 14 (2021); for discussion on racial disparities in residential care in Los Angeles see Frochen, Stephen, Ailshire, Jennifer and Rodnyansky, Seva,"Residential care in Los Angeles: Evaluating the spatial distribution of facilities and neighborhood access to care among older adults," (2019).

35   Frochen, et. al, (finding that "Older Hispanics suffer the greatest disparity in access to care among all groups. As their proportion increases in census tracts, predicted bed capacity decreases").

36   For example, Black and Hispanic households make up 66% of housing voucher holders. Fannie Mae, "Housing Choice Voucher Program Explained," (2022).

37   "CBOs are often central to the viability and life of communities, particularly urban African American communities. CBOs often develop as a response to the failure of government agencies and professional service providers to meet community needs". Griffith, Derek, Ober, Jule, Deloney E. Hill, Robinson, Kevin, Lewis, Yvonne, Campbell, Bettina, Morrel-Samuels, Susan, Sparks, Arlene,Zimmerman, Marc, Reischle, Thomas, "Community-Based Organizational Capacity Building as a Strategy to Reduce Racial Health Disparities," J Primary Prevent (2010) 31:31–39. See also Urban Institute, "Leveraging Community Expertise to Advance Health Equity, Principles and Strategies for Effective Community Engagement,"(July 2021,) finding that "Staff at CBOs are often experts in community matters, have earned the trust of community members over a long period, and can advocate and organize community members for policy and systems changes…CBOs often are culturally and linguistically effective and have more flexibilities to adapt and respond to changing community priorities than many governments or other private institutions…"

38   Donald Moynihan, Pamela Herd, Hope Harvey, "Administrative Burden: Learning, Psychological and Compliance Costs in Citizen-State Interactions," Journal of Public Administration Research and Theory, (Vol.25, Issue 1, January 2015,) at 43–69; Office of Management and Budget, "Study To Identify Methods to Assess Equity: Report to the President," (July 2021) at 22; see also Center on Budget and Policy Priorities, "States Can Reduce Medicaid's Administrative Burdens to Advance Health and Racial Equity," (July 2022); See for example Brodsky, Karen, The Commonwealth Fund, "Best Practices in Specialty Provider Recruitment and Retention: Challenges and Solutions," (August 2005).

39   Griffith, Derek, et.al, "Community-Based Organizational Capacity Building as a Strategy to Reduce Racial Health Disparities," at

31–39.

40   *Id.*

41   The Commonwealth Fund, "Low Reimbursement Rates are a Racial Justice Issue," (June 16, 2022); see also MALDEF, "Advocates File Lawsuit Alleging California's Separate and Unequal Medi-Cal System Violates the Rights of Millions," (Jul.12, 2017).

42   California Department of Social Services, The Community Care Expansion Program.

43   RCFE ALW Provider Training Manual (2009).

44   Center on Budget and Policy Priorities, "States can Reduce Medicaid's Administrative Burdens to Advance Health and Racial Equity,"(Jul. 19, 2022), citing Office of Management and Budget, "Study to Identify Methods to Assess Equity: Report to the President,"(Jul. 2021); White House, "Executive Order on Transforming Federal Customer Experience and Service Delivery to Rebuild Trust in Government,"(Dec. 13, 2021).

45   "Threshold Language" means a language identified as the primary language, as indicated on the Medi-Cal Eligibility Data System (MEDS), of 3,000 beneficiaries or five percent of the beneficiary population, whichever is lower, in an identified geographic area." DHCS, MHSD Information Notice No.: 13-09 (April 30, 2013), citing Title 9, CCR Section 1810.410 (a)(3).

46   LA Times, "More Californians are gaining broadband internet access. But Black and Latino households still lag," (June 2022).

47   This is unlike the DHCS assessment tool, an electronically scored tool using CMS's Minimum Data Set (MDS). CCAs use unvetted screening tools they create. See 2019 Waiver Application, p.23.

48   National Academy of Medicine, "An Equity Agenda for the Field of Health Care Quality Improvement," (Sep 15, 2021), citing Institute of Medicine, "Crossing the Quality Chasm: A New Health System for the 21st Century," (2001).

49   Hoffman, Kelly, Trawalter, Sophie, Axt, Jordan and Oliver Norman M., "Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites," PNAS, (April 4, 2016).

50   2019 Waiver Application, p. 36.

51   Justice in Aging, Comment on the Department of Health and Human Services' Office for Civil Rights (HHS OCR) Nondiscrimination in Health Programs and Activities Notice of Proposed Rulemaking (NPRM), (Oct. 3, 2022).

52   2019 Waiver Application, p.115

53   Health and Safety Code § 1569.616(c)(1)(J)) requires training "Cultural competency and sensitivity in issues relating to the underserved aging lesbian, gay, bisexual, and transgender community."

54   *See* SageCare, LGBTQ+ Training Course.

55   *See* CMS, Measuring and Improving Quality in Home and Community Based Services.