







October 5, 2023

Joseph Billingsley, Assistant Deputy Director Cortney Maslyn, Chief Department of Health Care Services Integrated Systems of Care Division 1501 Capitol Avenue, MS 4502 P.O. Box 997437 Sacramento, CA 95899-7414

Transmitted by email: <u>ALWP.IR@dhcs.ca.gov</u>

Re: 2024 ALW Renewal Comment

Dear Joseph and Cortney,

Justice in Aging, Disability Rights California (DRC), California Advocates for Nursing Home Reform (CANHR), Bet Tzedek, and the undersigned organizations are committed to protecting the rights of older adults and individuals with disabilities who rely on California's home and community-based services (HCBS) for their care needs.

We value the opportunity to comment on California's Medicaid Assisted Living Waiver (ALW) Renewal Application ("Application"). However, we are disheartened to learn, midway through the current 30-day commenting period, that the Application is a mere formality and does not provide any substantive changes to the ALW. Given that the Department of Health Care Services ("DHCS" or "Department") did not provide stakeholders with formal plans to which we can respond, the comments below pertain to the renewal Application as publicly posted.

The ALW is an important program in the spectrum of Medicaid HCBS that is available to older adults and people with disabilities. It is one of the few HCBS programs that allows low-income participants without a home the ability to remain in the community.









Since its original authorization in 2005, the ALW has undergone important changes to expand and improve on the program, often in response to stakeholder feedback. It is therefore disappointing that the current Application has not addressed the significant stakeholder concerns raised in recent years, or taken into account the growing need for ALW services. The Department's failure to make any improvements to the ALW is particularly unsatisfactory in light of the State's focus on reducing health disparities and its commitment to expanding HCBS in the Master Plan for Aging.¹

For example, DHCS is well-aware that ALW applicants spend 18 to 36 months on the program's waitlist. Yet, the Renewal Application does little to improve access: waiver administration is generally unchanged and waiver caps remain at inadequate levels. Also, despite the urgent statewide need for ALW services, the Application continues to limit the ALW to only 15 counties. And although publicly subsidized housing is the most community-integrated housing option available under the ALW, the Application fails to improve access to this option.

Our comments focus specifically on the following issues in the ALW Application:

- No expansion of waiver slots or geographic access despite the growing need and the persistent and lengthy waitlist.
- Failure to address disparities in access uncovered by California's LTSS Dashboard.
- Absence of consumer protections and resident rights, including those required for compliance with the HCBS Final Settings Rule.
- Absence of an explicit protection from unmitigated room and board rate increases by providers, in spite of DHCS's awareness of the significant risk posed to waiver participants who do not receive SSI income.

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¹ See MPA Initiative 24.

² Ibara, Ana, "'Operating Under Water: Families trying to place loved ones in Medi-Cal assisted living program wait years," (09/7/2022) available at https://calmatters.org/health/2022/09/medi-cal-assisted-living/.









- Lack of infrastructure investments or changes that would enable a statewide expansion of the waiver.
- I. DHCS Must Make Substantive Amendments to the 2024 Waiver Renewal to Address Limited Waiver Capacity and Ongoing Waitlists
 - A. Waiver Capacity is Inadequate and Fails to Address Unmet Needs (Appendix B-3)

The 2019 ALW Application set the cap for ALW participation at 5,744 participants for five years, which resulted in a waitlist of over 7,000 persons. In 2022, California received increased federal funding to expand HCBS under the American Rescue Plan Act (ARPA). DHCS elected to use a portion of this increased funding to eliminate the waitlist by seeking an amendment to the ALW to add 7,000 slots. Yet today, despite this increase, thousands of individuals continue to wait for waiver services.

The current Application resets the waiver cap at 5,744 and fails to account for the 7,000 slots added in 2022 despite the fact that the state's HCBS spending plan reflects an intent to retain the 7,000 slots, by including a \$38 million ongoing expenditure. We understand from DHCS that the omission of the 7,000 slots in the current Application was an oversight. We urge DHCS to formally clarify this in the Application.

But, even at the current capacity of 12,744, the ALW waitlist exceeds 3,000 individuals awaiting services. Accordingly, DHCS must expand available slots beyond the current 12,744 cap to meet this need. As in the HCBS-DD waiver, DHCS should plan for sufficient slots to cover the need rather than limiting the maximum number of participants served each year.

The program's extensive waitlist also leads to perverse outcomes. For example, the current and renewed Application require that 60% of new waiver enrollees transition from an institutional setting, and 40% enroll from community settings. This policy rightfully focuses on reducing institutional placements and supporting









community living. Unfortunately, as DHCS is well aware, due to the length of wait time for enrollment, individuals in community placement who urgently need waiver services are frequently advised to move into institutional settings in order to bypass the waitlist. Eliminating the waitlist by providing an adequate number of waiver slots is key to removing incentives to institutionalize waiver applicants.

Finally, the ALW must also be expanded to all of California's counties. Today, the ALW is available in just 15 counties. As nearly 20% of California's Medi-Cal eligible older adults and people with disabilities live outside of these counties and are unable to access the program, the decision to continue limiting geographic availability of the waiver is inconsistent with DHCS's commitment to addressing disparities in health and healthcare access.³ Because an expansion will require further capacity increases, we recommend that DHCS consult the HCBS Gap Analysis and other measures to ensure that capacity in a statewide waiver reflect regional needs.

B. Waitlist and Enrollment Administration (Appendix B-3)

Current guidance on ALW waitlist administration and spot allocation are laid out in the 2022 ALW amendment as well as in policy guidance in relation to the 7,000 slots added under ARPA funding.⁴ Unfortunately the proposed Application does not incorporate this additional policy guidance. DHCS needs to incorporate and reconcile the policy guidance and waitlist policy in the proposed renewal Application. In addition, DHCS must take additional measures to address inequities built into the waitlist administration process as it exists today, including:

https://www.dhcs.ca.gov/dataandstats/reports/Pages/HealthDisparities.aspx; https://www.dhcs.ca.gov/services/ltc/Pages/-MFP-Supplemental-Funding-Opportunity.aspx.

³ DHCS, (2023),

⁴ ALW PL #22-01









 Slot Release Policy Must Require Agency Performance Reporting to Protect Applicants (B-3) The Application is silent on how slots will be released to agencies. Under current policy guidance, DHCS determines how many additional slots are released to each waiver agency depending on the agency staff capacity, length of waitlist, and the number of slots an agency fills every month.

This policy rewards well-resourced agencies that can place individuals faster and move through their waitlist at a higher pace, but harms applicants who use an agency that has long waitlists or poor performance. Applicants have very little choice as to which agency is available to them since agencies serve the geographic regions in which they are seeking ALW placement. To the extent that an applicant may be able to select among multiple agencies, applicants do not have the information they need to make an informed choice since length of agency waitlists and agency placement rates are not publicly available. Because the ability of an agency to place individuals off its waitlist is heavily determinative of the wait times and the agency's ability of progress through its waitlist, the lack of transparency can lead to significant inequities in who gets access to the waiver and how soon.

DHCS needs to take the following steps to improve waitlist administration and equitable access to the waiver:

- Eliminate the ALW waitlist by increasing capacity to meet the need:
- In alignment with the soon to be finalized <u>HCBS Access</u>
 Rule, require waiver agencies to report waitlist length,
 demographics, average wait times on the waitlist, waitlist
 attrition rates, the average wait time between initial
 enrollment and receipt of services, and the percentage of
 authorized hours for each type of service under the waiver,
 including habilitation and personal care services. The
 agency's data should be published monthly on a dedicated









dashboard on the DHCS ALW website and on waiver agency websites to inform the enrollee application process and stakeholder improvement efforts, as well as enrollees themselves;

- Streamline and expedite processing of assessments and program enrollment after a slot has been allocated; and
- Prioritize progress through the waitlist based on imminent or critical need using the population prioritization criteria.
- 2. Actively monitor waitlist administration for inequities. (B-3) DHCS's recently published LTSS Data Dashboard documented racial and ethnic inequities in access to the ALW program, with white participants making up a disproportionately high share, and Hispanic and Asian participants disproportionately low share of waiver users. Yet the Application contains no measures to monitor or address disparities in access to the ALW services. In order to address disparities, DHCS must first ensure that the program is available to all who need it by increasing program caps to a level that addresses actual need, and eliminates the program's ongoing waitlist.

To the extent that the state continues to operate a waitlist, that waitlist must be monitored. Transparency and data collection are key to identifying and addressing inequities in waiver access. As discussed above, while DHCS publishes data on enrollment, there is no demographic data available on waitlist participation, wait times, or attrition. And, although in the 2018 renewal process stakeholders requested that DHCS at least directly communicate to applicants their place on the waitlist and expected wait times, the Department dismissed the request, stating that agencies are tracking waitlist placement and communicating with applicants. As a result, there is no way to assess disparities in waitlist administration. And, because waitlists and wait times are not









disclosed, individual wait times vary based on the applicant's waiver agency.

DHCS should add transparency measures and data collection activities into the Application, as will soon be required under federal regulations.⁵ Data measuring, at a minimum, access, utilization and quality should be publicly reported on the LTSS Data Dashboard and be stratified by demographic categories. Where disparities are identified, DHCS must establish benchmarks, in collaboration with consumer advocates and enrollees, to rectify inequities.

- 3. Amending Population Prioritization Categories. (B-3) The Application states that "enrollment may be prioritized based upon the imminent need for services that is determined through the assessment process." (27) DHCS should define what is imminent need for the purpose of prioritization. DHCS should add individuals currently experiencing or at imminent risk of homelessness and individuals leaving incarceration who meet the waiver's level of care requirements as priority groups. Prioritization must also consider the impact of intersectional identities on access, as a compounding of identities can result in increased risk of institutionalization.
- 4. Shift burden of submitting a complete waiver application to the waiver agency. (B-3) The proposed Application states that if a waiver agency fails to complete an application within 60 days, an "open slot will rotate to the next person on the waitlist and the requestor will be placed at the bottom of the list at their request or removed from the waitlist." This policy is unnecessarily punitive, imposing dire consequences on the applicant for a waiver agency's negligence. DHCS should give notice to individuals who

⁵ Ensuring Access to Medicaid Services CMS-2442-P(§ 441.303(f)(6)).









are to be removed or placed at the end of the waitlist, as well as provide additional time to submit the information directly to DHCS or to request support from the Department in getting the waiver agency to act. Where an application is not timely returned to DHCS due to waiver agency failure, DHCS should assist the applicant and any consequences should be borne by the agency.

DHCS must ensure that application and waitlist processes, as well as wait times are the same regardless of which waiver agency an applicant is working with. To that end, the Department must provide oversight over waitlist administration and waitlist processing. Where increased wait times are caused by low provider participation or insufficient service availability, DHCS must make strategic infrastructure investments to ensure supply meets regional needs.

II. DHCS Must Specify Consumer Rights and Protections in the ALW Application (Appendix F)

Without adequate enforcement mechanisms and consumer protections, waiver participants are at risk of rate increases, evictions, inequitable service quality and increased isolation. In addition, the failure to ensure that resident agreements contain federally mandated rights under the HCBS settings rule jeopardizes federal Medicaid reimbursement.

A. The ALW does not clearly outline non-SSI recipients board and care rate protections, leaving them at risk of eviction.

As we have discussed with you extensively, and summarized in our March 17, 2023 letter, the state failed to include clear room and board rate methodologies for non-SSI Assisted Living Waiver enrollees in the new waiver renewal Application. The Medi-Cal Procedures Manual applies the same rate methodology for SSI and non-SSI recipients but the Department has been hesitant to enforce rate









protections, stating that the only known way to be able to do so was to include the rate methodology in the new waiver application.

Failing to include these protections in the new Application places these participants at risk of facing steep increases to their room and board rates. The ALW is only available to individuals who are in the Aged and Disabled Medi-Cal program with no share of cost. Residents by definition have only a limited amount of income. Therefore, certified facilities should also be limited in how much they can charge.

Without this protection, residents may be evicted for nonpayment even though the provider was aware of the resident's limited income when accepting them into the facility, putting participants at risk of eviction, service disruption, and homelessness. DHCS must insert rate protections for *all* ALW recipients into the Application, prohibiting providers from charging *any* participant more than the SSI room and board rate. As discussed in our March 17th letter, DHCS should also amend contracts with providers to require adherence to this policy, and issue policy guidance to further educate waiver agencies and providers.

- B. The ALW Renewal Application Should Explain How Participants Will Receive the Minimum Resident Rights Protections Required under the Federal HCBS Settings Rule (Appendix F)
 - 1. Tenant Rights. The HCBS Settings Rule makes clear that all residents receiving Medicaid-funded HCBS in a provider-owned or controlled residential setting should receive at least the same or comparable protections from eviction that a tenant in a non-HCBS setting receives under the state or local jurisdiction's landlord tenant law.⁶ Effective implementation of this Rule necessitates

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⁶ For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for









including specific tenant protections in the waiver Application. While California law provides some RCFE-specific protections governing admission agreements, such as the limited circumstances under which a facility may modify agreement terms or rates, the limited grounds for eviction or discharge, and other protections, the law governing ARFs and RCFEs does not guarantee the same or comparable protections available under state or local landlord tenant law. DHCS has taken a first step in instructing providers regarding some of California's landlord-tenant laws by issuing Residential Rental Agreement Guidelines contained in Attachment X. However, these guidelines do not provide the full scope of eviction protections available to tenants under state and local laws.

For example, tenants in California are protected by a statewide Tenant Protection Act (TPA), with its just cause and rent cap protections. Notwithstanding the TPA's exemption of certain facilities from its protections, the HCBS settings rule's language is clear – at a minimum, comparable eviction protections and appeal processes must be provided. The Application must therefore ensure that ALW providers are affording state and local tenant eviction protections that are available to California tenants even if those laws exclude ALW settings. These include:

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each HCBS participant and that the document provides protections that address eviction processes and appeals comparable to those provided under the [state or local] jurisdiction's landlord tenant law. 42 C.F.R. 441.710(a)(1)(iv)(A). Words that are interchangeable with "comparable" include "equivalent to," "equal" or "as good as."

⁷ California's eviction protections are found at. Cal. Civil Code §§1946.2 *et seq.* Other California laws governing eviction processes and appeals are found at: Cal. Civ. Code §§ 789.3; 790 to 793; 827; 1925 to 1934; 1940 to 1954.05; 1954.50 to 1954.605; 1961 to 1995.340. In addition, 34 cities have adopted local ordinances offering greater eviction protections and processes to tenants:

https://www.tenantstogether.org/resources/list-rent-control-ordinances-city.









- Tenants living in a residence for a year or more must receive at least 60 days advance notice of eviction, and the eviction must be for "just cause." Cal. Civ. Code Sec. 1946.2(a);
- Tenants must receive a written explanation of the TPA just cause for eviction at inception of tenancy. Where "just cause" is based on a breach of a material term of the lease, there must be a specific notice with a right to cure. Cal. Civ. Code Secs. 1946.2(b)(1)(B) and (c); and
- All residential agreements must inform residents of local eviction laws where the local ordinance provides stronger protections such as longer notice periods and a right to counsel in the eviction proceeding.

DHCS has also mistakenly relied on provider self-certification to demonstrate compliance with this federal residential agreement requirement. Further, the self-certification tool used by DHCS does not include the specific tenant protections available to California tenants. Rather than relying on assurances by providers, DHCS must use reviewers knowledgeable about California tenant eviction protections to engage in ongoing review of individual providers' residential agreements in *all settings*, as well as actively scrutinize its policies and procedures to ensure compliance, a process that must include feedback from waiver recipients and advocates on behalf of older adults and people with disabilities.

2. **Choice of roommate.** DHCS' Beneficiary "Amenity" notice⁹ states that:

⁸ See, State Transition Plan Residential Provider Self-Survey Tool, Federal Requirement, Attachment XV, Question 6, at:

https://www.dhcs.ca.gov/services/ltc/Documents/Statewide-Transition-Plan-Compliance-with-Home-and-Community-Based-Settings-Rules-July-2023.pdf.

⁹ DHCS, (2023), https://www.dhcs.ca.gov/services/ltc/Documents/DHCS-0060-ALW-Amenity-Form.pdf.









"Each beneficiary of the ALW program is eligible and offered, at enrollment, the following benefits...:

- 1. Private or semi-private room with full bathroom (shared by not more than two beneficiaries). The choice of roommate is independent of the ALW.
- 2. Kitchenette, equipped with a refrigerator, a microwave (or cooking appliance) and adequate storage space for utensils and supplies."

The notice then gives the beneficiary the option to waive a private room, waive a refrigerator, and waive a microwave. Advocates hear from the community that in reality, beneficiaries often have little true choice about a private room, refrigerator, or microwave because very often the RCFE does not have a private room to offer. In other words, to receive services, beneficiaries have to waive one or all of the benefits, which violates the HCBS Settings Regulations. DHCS must ensure that the choice of a roommate is not dictated by supply issues, and work to identify sufficient providers to ensure true choice is available.

- C. DHCS must explicitly incorporate the HCBS Settings Rule community integration requirements into the renewal Application.
 - 1. Transportation. CMS guidance requires that services definitions be modified to "reflect the scope of non-medical transportation furnished under the waiver."¹¹ The Application merely confirms that transportation to medically necessary appointments or other services in the ISP is a service, and recognizes the use of public transportation as an option. This definition does not provide the level of integration that the HCBS setting rule mandates. At a minimum DHCS should require that the individual service plan

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¹⁰ § 441.301(c)(4).

¹¹ CMS, <u>Instructions</u>, <u>Application for a 1915(c) Home and Community-Based Waiver Technical Guide and Review Criteria</u>, <u>Version 3.6</u>, (Jan 2019).









include a community integration plan that reflects the needs and preferences of the participant, including all transportation options, shared rides, coordinated community outings and other available resources that would provide meaningful community integration.

2. Training & Compliance. DHCS is the state agency that is tasked with provider compliance and monitoring with the Setting Rule, a process inclusive of preventative and reactive actions. Activities DHCS will undertake to enforce and train both providers and agencies are missing from the Application's provider compliance oversight and monitoring strategies. The waiver Application should explicitly state that periodic and ongoing training and compliance monitoring is compulsory.

The Application should include specific mechanisms to identify non-compliance including grievance filings by participants and periodic audits. The outcome of non-compliance should not put waiver participants at risk of losing services (see Appendix C, p. 56, 64, 68). Consequently, the state must outline the procedures to guarantee that, should a provider be removed from the waiver program due to noncompliance, residents are able to successfully transition to alternative locations of their choice where they can continue receiving ALW services.

3. Grievance Procedures. DHCS must incorporate the grievance procedure laid out in the STP into the Application. We are disappointed to note that in spite of multiple conversations with the Department, including a letter sent on March 23, 2023, requesting that the state create a grievance procedure for ALW participants and applicants, the Application fails to include any grievance process. This is surprising in light of California's reference to a DHCS grievance procedure in its final STP that would allow ALW participants to file a complaint with the Department about noncompliance with the Setting Rule. The STP or any other grievance









procedure is absent from the Application, except to state that agencies should ensure that individuals are "informed regarding the ALW's informal grievance procedures and formal appeal rights, termination procedures, and rights to refuse or discontinue services." (See also Appendix F-3, "State Grievance/Complaint System," which DHCS left blank.)

We request that the procedure laid out in page 45 of the STP be a) incorporated into the ALW application and b) extended to include all complaints about ALW waiver agency and provider services. In anticipation of the soon finalized HCBS Access Rule, DHCS should include assurances that the outcome of grievance filing should not put a complainant at risk of loss of services, including due to retaliation or failure to comply with a Corrective Action Plan by the provider, 12 and ensure that such information is accessible for individuals with limited English proficiency. Data on grievances filed and their outcomes should be collected and published on the LTSS Data Dashboard.

D. DHCS Must Include Substantive and Significant Amendments to the Performance measures in the renewal Application

We suggest, respectfully, that performance measures be completely rethought. As you know, CMS last year released a recommended quality measure set. The CMS measure set addresses waiver subassurances related to service planning, and health and welfare. Accordingly, the CMS measure set includes information on whether services are actually delivered in accordance with the service plan, and whether "the state establishes overall health care standards and monitors those standards based on responsibility of the service

¹³ CMS, Home and Community-Based Services Quality Measure Set, SMD #22-003 (July 21, 2022).

¹² Ensuring Access to Medicaid Services CMS-2442-P (§ 441.301(c)(7).









provider." The proposed measure set also addresses three key priority areas: access, rebalancing, and community integration. 14

The performance measures proposed in the renewal Application, however, fall far short of the standards set forth in the recent CMS guidance. These performance measures are not particularly useful – they have little to say about the quality of care received by program participants. Instead, the measures compile relatively unimportant (or obvious) data about the operation of the ALW eligibility determination process. The measures appear to be driven largely by the availability of data, rather than its usefulness.

For example, the ALW requires that an applicant's clinical eligibility be assessed by a registered nurse, using a specified tool, and a related performance measure determines the percentage of clinical assessments performed by a registered nurse. Presumably this percentage in practice will be 100 percent, with rare exceptions. This type of measure does very little to improve the lives of the assisted living residents receiving ALW services. Other measures have similarly little value.

Accordingly, we recommend that the measures be substantially rewritten to be consistent with the recent CMS guidance. The measures should focus on the participants' experience to better measure access, health and welfare. California's performance measures should also be made available to the public. As you know, Justice and Aging had to make a Public Records Act request and then sue the Department in order to review the measures. We believe that this is an indictment of current practices. Quality measure data should be easily accessible to the public on the Department's website. Public measure data is of little use if it is merely shared tightly between the Department and CMS.

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¹⁴ Id. at 7-8.









E. DHCS Must Improve its Transparency and Stakeholder Engagement

Finally, we are concerned with DHCS's lack of transparency and communication in regards to the future of the ALW program. Although DHCS invited stakeholder participation in its plans to integrate the HCBA and Assisted Living waivers, the Department's failure to engage the entire workgroup in its decision to abandon the integration plan reflects a lack of commitment to a true stakeholder process.

We have just recently learned from DHCS midway through this stakeholder period that the state is no longer proceeding with the waiver integration and that the two programs will be carved into managed care. The lack of transparency regarding the future of the ALW deprives advocates of a meaningful opportunity to provide comments on the ALW Application.

Whatever course DHCS takes in the future – whether integrating the ALW with the HCBA waiver or carving the assisted living benefit into managed care—making improvements to the current waiver as we suggest throughout our comments puts the state in a better position to advance those goals. For example, removing geographic limitations is key to reducing inequities in access to the ALW program, and to addressing significant unmet needs among the state's low-income older adult population. The renewal presents an opportunity to lay a needed foundation to make the ALW available in all California counties.

DHCS can also use the renewal as an opportunity to bolster the availability of ALW services in publicly subsidized housing by clarifying that these settings include supportive housing, those paid for through a HUD voucher, and other forms of community housing in which individuals may access home health agency services.









We are committed to ensuring that California's ALW program is equitable, accessible, and meets the needs of California's low-income older adults and adults with disabilities so they can continue living in an integrated community setting, as envisioned in *Olmstead*. We hope DHCS shares this commitment, and uses the renewal process to improve program equity, quality and access.

Sincerely,

Hagar Dickman Senior Attorney, Justice in Aging

Elizabeth Zirker Senior Counsel, Disability Rights California

Pauline Shatara Deputy Director, California Advocates for Nursing Home Reform

Kim Selfon Medi-Cal and IHSS Policy Specialist, Bet Tzedek

Alameda County Older Adults, California Disability-Aging Community

Healthy Results Action Network (CDCAN)

Alzheimer's Los Angeles California Long Term Care Ombudsman

Association

Caring Across Generations

Alzheimer's Orange County Cardea Health

California Alliance for Retired

Americans

Americans

California Commission on Aging Choice in Aging



MentalHealthHookup.org







The Coalition for Housing Moffats Rose Home Accessibility (CHANCE) **EDC Long-Term Care** National Health Law Program Ombudsman Program FREED Center for Independent Operation Ground 0 Inc. Living **Grossmont Gardens Assisted** Placer Independent Resource Services Living Jewish Family and Community Senior Advocacy Services of the North Services East Bay Bay Senior Services Coalition of Alameda Jewish Family Service LA County JLA Special Needs Trust & Stone Mountain Medical Associates, Services Inc. Konocti Senior Support United Way of Greater Los Angeles Legal Assistance for Seniors Western Center on Law and Poverty Williams Whittle Residential Care Los Angeles LGBT Center Homes Malloy Care Management LLC Derek Hauser, DO Marin Center for Independent Linda Mellen Living **Matters of Care**