December 8, 2014

Toby Douglas, Director
Department of Health Care Services
1501 Capitol Avenue, MS 4503
Sacramento, CA

Re: Comments on California HCBS Statewide Transition Plan

Dear Director Douglas:

Thank you for the opportunity to comment on California's current draft (dated 11/7/14) of the statewide transition plan for complying with the new Medicaid home and community-based services (HCBS) regulations.

Below, please find our joint comments on the draft plan. These comments incorporate some of our previous comments to highlight certain ongoing issues. We are attaching our previous comments and are incorporating them by reference because many of the comments remain relevant.

We understand that development of the transition plan is a lengthy process that is anticipated to involve multiple iterations. We request to be able to speak with your staff on an ongoing basis to discuss the drafts and our suggestions. Please contact Eric Carlson ((213) 674-2813; ecarlson@nsclc.org) with questions and to set up a time to discuss.

Thank you for your work on this important transition process.

Sincerely,
California Foundation for Independent Living Centers
California State Council on Developmental Disabilities
Congress of California Seniors
Disability Rights California
Disability Rights Education and Defense Fund
National Health Law Program
National Senior Citizens Law Center

December 8, 2014

Draft Transition Plan Comments from the California Foundation for Independent Living Centers, California State Council on Developmental Disabilities, Congress of California Seniors, Disability Rights California, Disability Rights Education and Defense Fund, National Health Law Program, and the National Senior Citizens Law Center

Thank you for the ongoing opportunity to comment on California's draft statewide transition plan for complying with the new Medicaid home and community-based services (HCBS) regulations. We believe strongly in the principles behind the regulations — that HCB settings are truly community based and that participants enjoy respect and freedom of choice in HCBS programs.

We understand that the Department intends to submit a transition plan to the Centers for Medicare and Medicaid Services (CMS) in December 2014, but that any plan approved by CMS will not be the last word, because additional transition plans and policies will be developed in subsequent months and years. We appreciate that transition involves a multiplicity of issues and actors, and understand why the development of a transition plan will be an ongoing enterprise.

Listed below are some issues that we believe deserve attention. Please feel free to contact us to pursue any of these issues further.

1) **Seek Short Delay to Allow Adequate Time for Consumer Input**

As we pointed out in earlier comments, the state is following an extremely compressed timeline for the development of this initial transition plan. We repeat our request that the state seek additional time from CMS so that this initial transition plan can address issues in a less cursory fashion. As the entire transition process will require multiple years and utilize additional iterations of the transition plan, there is no reason why submission of the original draft transition plan cannot be pushed back by one or two months. Outreach to HCBS consumers and their families has been minimal, and consumers have voiced frustration at inability to access the draft plan.1

[1] During the Department's single stakeholder call on the second draft on December 2, stakeholder comments included concern that the draft plan was not accessible for individuals without access to the internet.

CMS should allow the state more time to reach these stakeholders and allow them to provide input on the services that are critical for them. Such a moderate delay would be in the best interests of the state, providers, and consumers. Under the federal regulations, the public input process must be "sufficient in light of the scope of the changes proposed, to ensure meaningful opportunities for input for individuals serviced, or eligible to be served, in the waiver."2 We believe that, under the state's current compressed schedule, the public input process does not meet this requirement, with the result that consumers do not have an adequate opportunity to be heard.

2) Follow Consistent Principles, Across State Departments, in Implementation of the Federal Regulations

As set forth on page 3 of the draft transition plan, the state's HCBS waivers are administered by various state entities. The MSSP Waiver, for example, is administered by the Long Term Care and Aging Services Division of the Department of Aging, while the HIV/AIDS Waiver is administered by the Office of AIDS of the Department of Public Health, and the DD Waiver is administered by the Community Services Division of the Department of Developmental Services.

We believe that each of these state agencies should follow consistent principles in implementation of the federal regulations. It should not be the case that, for example, the Department of Aging follows certain principles and/or implementation policies and procedures while the Department of Developmental Services follows different principles and policies. The new federal regulations are based on important overarching principles, and it is important that those principles be honored consistently across state government.

3) Take Steps to Obtain Robust and Candid Stakeholder Input

The state's draft transition plan says on page 11 that "[s]takeholders will be encouraged to participate and provide input to the assessment process." For this input to be to be meaningful, the assessment process must be consumer-friendly. We recommend that assessment tools be specifically designed for use by HCBS participants and their family members. For example, assessment tools may be developed with a question-and-answer format that uses no jargon, assumes no

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[2] 42 C.F.R. § 441.304(f)(1).

preexisting knowledge of the federal regulations or the relevant public policy, and uses plain language and real-life examples so the questions will be understandable and meaningful.

The state should take steps to ensure that consumer input is not improperly influenced by service providers. It would not be a reliable process, for example, to have consumer assessments obtained by a HCB service provider, since such a service provider would have a clear interest in the consumer's conclusions. For assessment results to be trustworthy, assessments must be administered by persons or entities without a conflict of interest.

Also, the state should develop multiple means of accepting stakeholder input. As we stated in earlier comments, the state should not rely exclusively on submission to an e-mail address, as many consumers may not have meaningful access to the internet or to e-mail. One good option is the convening of focus groups for the sharing of personal experiences. Focus groups should be local for, and easily accessible to, consumers, with consideration of issues that may affect a consumer's ability to participant in such a focus group, such as accessible and public transportation, prior notice provided, time of day, and the incorporation of translation for individuals with communication disabilities and/or Limited English Proficiency. At a minimum, the state should be prepared to accept and distribute assessment information for stakeholder input through multiple channels, such as: mail, website, a dedicated telephone number and fax.

As we have commented before, the state should provide education on the HCBS regulations so that participants and other stakeholders may provide more meaningful feedback on their own experiences. Georgia's transition plan, for example, provides for stakeholder training and education from September 2014 through April of 2015.

Any training should include person-centered planning, consistent with the draft transition plan's discussion of person-centered planning on page 14. Training also should include a discussion of the significance of the *Olmstead* decision and an individual consumer's right to live and receive services in the least restrictive setting. Education should include clear information about what may be changing (and what is not) and, once the procedures are developed, how a consumer may complain about a community-setting that is not following the rules.

4) Provide Transparency in Transition Plan Activities

Transition implementation will involve many changes to policies, procedures, and processes. Throughout these changes there must be transparency so that all parties affected will understand what alterations are being considered and how parties may provide input. A lack of transparency causes confusion and misinformation, which can be very destabilizing.

Accurate assessments of providers are key to implementation, and these assessments must be transparent so that interested parties have opportunities to provide additional information to the state. A key feature of transparency is to publish the list of providers and whether or not, even initially, they meet the community-based setting requirements. Any appeal process must also be transparent and involve setting consumers.

An initial step in transparency is creating a communication plan that will identify how and when information will be available to the public. Such a plan will ease concern stemming from lack of knowledge about state action and allow stakeholders to plan for providing feedback. This feedback is critical to the state understanding the effect of changes and what consumers identify as necessary to achieve the integration promised by the federal regulation.

While transparency may seem initially laborious, it is necessary to successful long-term implementation. Without transparency, the state may spend significant resources going back to duplicate efforts after information has been received subsequent to initial decisions.

5) Provide Specifics in Assessments, So As to Allow for More Meaningful Responses

In several instances, the federal regulations set standards that are broad and non-specific. For example, settings must support "full access … to the greater community," provide opportunities to "engage in community life," and ensure "rights of privacy, dignity and respect."

An assessment tool, in addressing such requirements, should provide greater specificity by using examples. Regarding dignity and respect, to pick one example, an assessment tool might inquire whether HCBS participants are addressed by name, or whether staff instead refer to participants by last name or room

number, or as "sweetie," "hon" or some other shorthand nickname. Regarding privacy, similarly, an assessment tool might ask whether participants' personal information (medication lists, for example) are posted in public view. On the issue of accessibility, an assessment tool should ask whether participants are able to independently go to and enter all areas of the residence when they wish, including using elevators, because they may not realize that having to wait in the hallway for someone who can see or reach the buttons is a facet of inaccessibility.

These examples are a non-exclusive list. The overarching point is that, in some instances, developing an assessment tool with the bare language of the federal regulations will not be productive. Both providers and participants will need more detail as to the types of practices that are considered compliant or non-compliant.

6) Involve All Relevant State Departments

As we have pointed out previously, the state's HCBS waivers involve state agencies other than those that administer the waiver. The assisted living waiver, for example, is administered by the Long-Term Care Division of the Department of Aging, but the licensure and inspection of Residential Care Facilities for the Elderly (RCFEs, the facilities where assisted living services generally are provided) are handled by the Department of Social Services (DSS). Likewise, the DD Waiver is administered by the Department of Developmental Services (DDS) but community care facilities funded by the DD Waiver are licensed by DSS.

DSS is heavily involved in the setting of facility standards and, accordingly, it should be actively involved in the development and implementation of the state's transition plan. This is especially the case if DDS, in conjunction with DHCS, will be taking an active role in ongoing monitoring and enforcement of the transition plan as a part of its licensing function. More generally, the state's development of the transition plan should include any state entity that is closely involved with a setting's operation, including collaborating or partnership entities, such as those relating to housing or employment.

Consistency among departments in the early part of the transition plan is especially important so that programs move forward in implementation in a similar way. Assessment tools and on-site reviews should use the same tool, with supplemental pieces if necessary for different programs. Any supplements or

changes to an assessment should be cleared through a process that maintains consistency, includes public comment, and ensures that community is judged consistently for all types of consumers. Allowing for differences in populations and individuals must not degrade the ideals of community life and engagement.

In the near term, involvement of all relevant state entities is essential for development of the best possible transition plan. For the longer term, the involvement of all relevant entities will be essential for, among other things, ensuring ongoing monitoring and compliance.

7) Conduct an Adequate Number of On-Site Evaluations

The draft transition plan on page 13 refers to a sample of settings being selected for on-site evaluations. We recommend that the state conduct as many on-site evaluations as possible, across every HCB setting category, in order to get the most accurate information about HCB settings. We also remind the State that if it is planning to submit any sites to the heightened scrutiny process, it should perform an on-site assessment of that site.3

As mentioned previously, there may be issues with self-assessments based on the types of questions asked or sources of bias. On-site assessments must be compared to original self-assessments so that the reliability of self-assessments can be determined. If accuracy is low, the Department must reassess the process used and develop corrective policies to more accurately determine the community nature of the settings. This may include increased on-site evaluations or conflict-free interviews during the person-centered planning process to examine the consumer's experience more in-depth.

The state should utilize a variety of methods to determine compliance about the largest possible number of settings. This may include a self-assessment tool for both consumers and providers, as well as the consumer and family input process, person-centered planning process, and at least for DD Waiver Funded Settings, the National Core Indicators (NCI) already conducted by area boards. NCI, using

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[3] CMS, Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Setting Requirements 4 (Sept. 5, 2014) ("In instances where a system review identifies settings which are presumed not to be home and community based and the state intends to submit evidence that the setting is home and community-based and does not have institutional characteristics, CMS would expect an onsite assessment that supports the state's assertion.")

the crosswalk tool developed for the HCBS rules, can be useful to flag potential problem areas, realizing the sample size is likely too small to provide useful information on specific settings or types of providers. Like used in Indiana's transition plan, the NCI may be useful in indicating inaccurate self-assessments.

We respectfully suggest that the number of on-site evaluations should not be based ONLY on statistical-significance algorithms. The most powerful result of an on-site evaluation is moving that setting towards compliance. The purpose of on-site evaluations is *not* merely to reach conclusions regarding the settings generally. Thus, the number of on-site evaluations should not be limited to the number of evaluations needed to obtain statistical significance for evaluation findings.

Indeed, statistical significance is not meaningful for information obtained from the on-site surveys. Assume, for example, that a statistically-significant sample found that a majority of RCFEs were out of compliance with a particular provision of the federal regulations. The response to this finding certainly would not be to disqualify RCFEs, or some significant percentage of RCFEs, from HCBS reimbursement. Instead, the state would seek to demand compliance on an ongoing basis for those RCFEs seeking to participate in the assisted living waiver.

8) Ensure Significant Consumer Participation in On-Site Evaluations

The draft transition plan, on page 13 states that "[t]he on-site evaluations will be conducted by a survey team that includes representation from at least two of the following: State personnel, service recipients or their family members, case managers or other representatives of case management entities, licensing entities, representatives of consumer advocacy organizations, and/or other stakeholders." This strategy, however, does not provide for adequate input from consumers, whose interests are at the center of the new federal regulat1ions. Ideally, every team would include a consumer or a representative of a consumer advocacy organization. The current draft, however, contains no assurance that *any* team would include a consumer or a consumer advocacy representative.

9) Protect Consumer Rights Throughout the Transition

For most HCBS participants, continuity of care is critical for successful community integration. The HCBS rules will advance community integration and will likely

involve changes to settings or even consumers changing settings. A transition plan must be realistic that changes will occur. It should include protections for consumers, consider timing for when providers must come into compliance, allow for appeals, and establish procedures for individual transition plans.

The transition plan timeline must consider when provider review and compliance deadlines will occur. Transition plans should allocate adequate time, and provider compliance plans should not all terminate around the same date as such an action could create more instability than is necessary. The initial provider review process and timelines must not end before a process is available to help consumers smoothly transition to new services or providers. The transition plan for HCBS must ensure stability for individual consumers.4 There should be protections in place for consumers who reside in facilities that may choose to close or change populations served.

10) Ensure that Facilities are Compliant for all Consumers

In order for a facility to be considered community-based, it must meet the HBCS standards for a community setting for all residents, regardless of a resident's payment source. The federal regulations set forth five qualities of community based settings, with additional requirements for provider owned or controlled settings. The setting must meet these five requirements to provide community based services and adhere to the regulations regarding provider owned or controlled settings. A facility must comply with these regulations for all residents, regardless of payment source, in order to remain faithful to the regulations.

If a facility does not meet the requirements of community based settings for some, those characteristics will affect the experience of other consumers. For example, the rules require that a setting ensure the individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.5 If a facility is allowed to use restraints on a non-HCBS funded resident, that will affect the experience of the HCBS-funded resident and cause the facility to have characteristics of an institution. Another example would be a facility with different rules for privacy. If the HCBS funded residents see others being punished

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[4] CMS has issued guidelines in the Statewide Transition Toolkit regarding what is required in the plan when relocation of beneficiaries is part of the state's remedial strategies. These protections should be part of all state plans because it is likely that at least some consumers will have to move or change settings. *Id.* at 5.

[5] *See, e.g.,* 42 C.F.R. § 441.301(c)(1)(4).

or chastised for trying to take the house phone into their room for private phone calls, the HCBS funded residents are not likely to assert their right to privacy. As a practical reality, many individuals do not want to assert rights or privileges that their housemates may not have, especially if they consider their housemates their friends.

The community nature of a setting is supposed to focus on the experience of an individual. If the treatment of non-HCBS funded individuals does not meet the community-based setting requirements, these non-community characteristics will affect the experience of all residents, regardless of funding source. The Department should require that HCBS settings honor the new HCBS standards regardless of a participant's source of payment (including private payment and non-HCB Medicaid payment). A contrary interpretation would condone payment-source discrimination that would be contrary to both the letter and the spirit of the new regulations.