October 20, 2014

Toby Douglas, Director Department of Health Care Services Sacramento, CA

Re: Comments on California HCBS Statewide Transition Plan

Dear Director Douglas:

Thank you for the opportunity to comment on California's draft 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. We hope to meet with your staff to discuss the draft and our suggestions for the transition plan. Please contact Eric Carlson ((213) 674-2813; ECarlson@nsclc.org) with questions and to set up a time to discuss.

Sincerely,

The Arc of California
California Foundation for Independent Living Centers
Disability Rights California
Disability Rights Education & Defense Fund
National Health Law Program
National Senior Citizens Law Center

Draft Transition Plan Comments from The Arc of California, California Foundation for Independent Living Centers, Disability Rights California, Disability Rights Education & Defense Fund, National Health Law Program, and National Senior Citizens Law Center:

Thank you for the 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 participants enjoy respect and freedom of choice in HCBS programs. After reviewing the draft, we conclude that the plan is, at this point, primarily a proposal for the Department's future development of a draft plan. Moreover, the current document offers stakeholders an opportunity to comment on those components that are contained in the draft framework, but not on the underlying assumptions and process behind the draft.

We would like to ask the Department to take a step back and adopt an inclusive stakeholder approach that mirrors the CMS final rule, which places the person-centered planning process at the heart of how HCB settings should be evaluated. Stakeholder involvement, and consumer input in particular, must play an originating and not merely validating role in the planning process. The new Medicaid HCBS regulations mark a sea change for HCB settings. An adequate transition plan must first take full account of how current HCB residents and consumers experience community inclusion and freedom of choice, in order to plan for the regulatory changes and implementation strategies needed for compliance with the new rules. The single best source of consumer experience are the consumers. As consumer and advocacy organizations, we would like the opportunity to work closely with the Department and our constituents to envision a new roadmap forward on developing and finalizing California's HCBS transition plan.

We appreciate the Department initiating the process for complying with the rule. Our comments focus on two parts:

Part 1: Framework Recommendations for Draft Transition Plan

Part 2: Essential Elements to Include in Transition Plan

We look forward to working with the Department to ensure that the regulations' promise is realized.

PART 1: FRAMEWORK RECOMMENDATIONS FOR DRAFT TRANSITION PLAN

I) Adopt A Realistic Timeline That Allows For Necessary Consideration Of Stakeholder Input

The current framework is incomplete. A one month comment period on a general framework is insufficient to conduct the outreach and assessment required of a draft transition plan. As indicated by our subsequent comments, we believe the State has yet to develop a draft plan, and the development of a draft plan cannot possibly be complete by the limited period of time currently allocated by the Department. Instead, we propose that stakeholders, including consumers of the services at issue, be included in the development of the transition plan. The transition plan should set realistic timelines for completion of certain activities, along with benchmarks for incremental changes so that consumers do not have to wait until the final product to realize the benefits of the new regulations.

We understand that the Department is working under a 120-day time frame set by the regulations, but also observe that, in practice, CMS and the states are operating under timelines in which transition decisions will be made long after the expiration of the 120-day deadline. In most states — arguably, in all states — the "transition plan" is in reality a work plan that contemplates that most substantive decisions regarding transition will be made months or years after approval of the "transition plan."

Under Georgia's proposed transition plan, for example, the state proposes to develop a "transition plan package" over the 18 months concluding at the end of 2015. Colorado's proposed transition plan, similarly, contemplates that many important activities will not *begin* until 2015 or 2016. In most cases, for example, the work to revise the Colorado HCBS waiver applications or relevant state regulations will not begin until November 2015; likewise, development of a model lease will not begin until January 2016.

In California itself, according to the Department's proposed transition plan, many important decisions regarding transition are not scheduled to be made until 2015 or later. For example, the Department has proposed a deadline of six months after CMS approval of the transition plan for "initial State-level assessment of standards, rules, regulations, and other requirements," and development both of an assessment tool and a provider appeal process.

The reality is, as CMS and the states are experiencing, that development of a comprehensive transition plan is a process requiring multiple years. Given that long time frame, and the importance of starting with a solid work plan, it is unwise for the Department to build a transition plan on this very general framework and only allow one week for consideration of stakeholder feedback, prior to the scheduled release of a second draft on or about October 27.

The HCBS regulations were released and therefore known on January 16, 2014, and the Department thus had several months to solicit stakeholder input generally, and develop a collaborative transition plan, prior to September 19. The Department's inability to do so should not deprive stakeholders of a meaningful draft HCBS plan, with a realistic opportunity to have input considered for the next iteration.

The current process for stakeholder input, and the failure to include clear opportunities for such input in the proposed plan, cannot be considered to 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," as is required.¹

For all these reasons, we request that the Department modify its current framework and allow the time and resources necessary to develop a draft transition plan. If necessary, we suggest that the Department request from CMS a reasonable extension of the 120-day time frame. It is in the interests of stakeholders, the Department, CMS, and particularly Medi-Cal HCBS participants, that the Department have a realistic opportunity to

-

¹ 42 C.F.R. § 441.304(f)(1)

develop a plan that has built-in opportunities for stakeholder involvement and formal feedback.

II) Develop A Plan Based On Robust Stakeholder Outreach And Feedback

As the state develops the draft transition plan, we have several recommendations for seeking stakeholder feedback. First, accepting comments only by email is not as effective as reaching out to consumers directly to solicit input directly from consumers in other ways, including, minimally, providing a mailing address for comments. Given the challenges of electronic communication (requires literacy, consumers often need their providers to help which may chill their honest input, requires access to a computer and computer literacy), we fear that the Department is missing an important opportunity to hear directly from consumers. On October 2, we wrote to you encouraging you to attend the October 9-10 Supported Life Conference, where several hundred people with developmental disabilities would be in attendance. We also encouraged you to reach out to consumer groups such as CFILC, SILC, and People First groups in the state to work collaboratively to obtain the most robust consumer input possible. We hope that you are working on how to best solicit and consider consumer input, which should include in-person, individual and small group opportunities to share their personal experiences.

Moreover, we encourage you to increase consumer involvement in the following additional ways:

1) Educate participants about their rights to fully integrated settings so that they may provide meaningful feedback on their own experiences. This information is crucial to the State's compliance in the short and long term. Other states' plans include participant education. Georgia's plan, for example, provides for stakeholder training and education from September 2014 through April of 2015 to make sure that individual HCBS participants, their families, and similarly situated stakeholders will understand changes they can expect to see and which will affect services.

- 2) Ensure that the assessment teams that are described in the draft transition plan always include consumer representation and meaningful consumer participation.
- 3) Develop a means for consumers to participate in their own self-assessment of the settings in which they live or spend their days. Participant assessments must be accessible to the individual, free from provider influence, and part of the assessment validation process. We do not believe that provider self-assessment is at all adequate to determine compliance with the HCBS regulations.

III) Use Person-Centered Planning to Inform Consumers, Approach Compliance, and Gather Information About Settings

Person centered planning requirements in the HCBS regulations are currently in effect. Under those requirements, consumers' planning processes should comprehensively evaluate their current settings to determine if they comply with the HCBS regulations. To do so, the teams should consider whether the settings where consumers reside and spend their days are community-based, are the most integrated setting appropriate to their needs, whether they have sufficient supports for the most appropriate setting, and whether changes need to be made to their plans. If needed to address the address the issues above, the consumer's person-centered plan should identify whether a new setting and/or new supports are needed, what can be done immediately, tasks and assignees, and a timeline that will redress the issues as quickly as possible.

In addition, the person centered planning provides opportunities for information gathering about consumers' experiences in their current settings and their preferred settings; this information will help identify compliance issues and help ensure the Department has a proper array of HCB services and settings. This should be a priority issue.

IV) Involving Other State Departments In Developing The Draft Transition Plan And Ongoing Review

We are reassured by the draft's initial identification of the California Department of Public Health (CDPH), the Department of Developmental Services (DDS), and the California Department of Aging (CDA) as members of the state's current HCB program administrative teams. Given the importance of these state partners during the transition period, and especially for the purposes of regulatory review and ongoing licensing and monitoring of HCB settings, they require an explicit role within the transition plan itself. CMS' new HCBS rule involves not only a transition for HCB settings and providers, but also for the state departments and on-theground personnel who will be responsible for administering the rule within California. All departments that have responsibility for the review, licensing and assessment of HCB settings, and who work with HCBS program consumers, will have expertise and best practices to share, as well as the capacity to take on specific responsibilities during and after the transition period. The State entities identified should also include those collaborating or partnership entities, such as for housing and employment, where they will be part of implementing services or where they have information that will aid in a smooth, complete implementation of true community services.

The particular ongoing involvement of the Department of Social Services (DSS) and DDS with certain HCB settings also should be included in the State's plans to monitor settings for compliance. As we explain below, establishing settings' compliance should not be a one-time activity; to best protect Medi-Cal HCBS participants, they must have access to a mechanism that can investigate complaints and compel compliance. Because DSS has a preexisting duty to monitor the settings that it licenses, and DDS performs quality assurance reviews, these departments are well-equipped to include compliance with the HCBS regulations as a component of their ongoing interactions with owners and operations of HCB settings.

Other states' transition plans have included the relevant licensing agencies. In Georgia, for example, the transition plan includes the Healthcare Facility Regulation Division of Georgia's Department of Community Health. Under the plan, Georgia intends to review licensing standards, consider potential changes to licensure regulations, and implement a plan to achieve provider compliance with licensure standards. Colorado's transition plan similarly includes Colorado's Department of Public Health and Environment. One section of Colorado's transition plan addresses "Modifications to Licensure and Certification Rules and Operations." California should take a similar approach and involve both DDS and DSS in this process.

PART 2: ELEMENTS TO INCLUDE IN THE DRAFT TRANSITION PLAN

We urge the Department to incorporate our recommendations in developing the Transition Plan. In addition to our process recommendations above, we offer suggestions of substantive elements the Department should address as it develops the draft transition plan. Based on a review of other states' plans, we believe the draft transition plan should not only identify issues and action items, but should indicate the expected start and end dates, a description of the activity, the State agencies and departments responsible, stakeholder groups involved, and the expected outcome. While not an exhaustive list, here are key issue areas that must be addressed in the draft transition plan:

ISSUE AREA	DESCRIPTION
Identification of Stakeholder Involvement	Clear identification of stakeholder involvement, including when and how stakeholders will be involved in development, when there will be opportunities for comment, and other opportunities for participation. Processes that need feedback loops, such as assessments of providers, will be clearly identified. Specific processes for robust consumer involvement, including individual and group interviews and focus groups, must be included, as well as consumer self-assessment of their living arrangements and day programs.
Identification of HCBS Providers	Including site information and category of service provided. Provided to the public, this information will allow the Department to gather information about the settings.
Address Non- Residential Settings	That CMS has yet to provide specific guidance regarding non-residential settings does not absolve the state from its obligation to include non-residential settings in the compliance determination process. Forthcoming CMS guidance will not alter the fact that the regulations apply to all HCBS settings, including non-residential settings. Gathering information from the public and stakeholders on this issue, evaluating rules of

	such settings, and doing an inventory of non-residential settings will give the departments an informed basis for action when forthcoming CMS guidance is issued.
Identify Settings that are Presumptively Institutional	Prioritize types and specific settings—both residential and non-residential that are "presumptively institutional" to share with the public for input and comment. Evaluate rules and policies related to such settings, including provider qualifications, on an expedited basis.
Prioritize Assessments for Settings Presumed Institutional	Prioritize individual assessments of programs and facilities that are identified as presumptively institutional. This will allow the Department to take speedy steps to come into compliance with the HCBS regulations. A plan for compliance must provide for opportunities for stakeholder input and must focus on participant experience and access to the community. This would include evaluating individual placement in such settings pursuant to the person-centered planning process, and making any appropriate adjustments toward increasing community integration. Such process must incorporate such elements as the individual's wishes and goals, medical opinion, and a review of HCBS options.
Individual Transition Plans for Consumers	The Department must identify a timeline for developing a process to help consumers who may need to transition to different services. This timeline must coincide with provider review such that consumers are not losing service providers before a process is available to help them smoothly transition to new services or providers. The transition plan for HCBS must ensure stability for individual consumers and not decrease their community interaction.
Appeals of Determination that a Setting Is/Is Not HCB Compliant; Individual Consumer Appeals	In addition to the provider appeal described in the draft transition plan, in which a provider may appeal a determination that a setting is not HCBS regulation-complaint, consumers should have the opportunity to appeal a determination that a setting is HCBS regulation-compliant. In addition, a specific process needs to be developed so there is an individual appeal process available for consumers whose

Comprehensive Assessment Process Conducted by an Independent Third Party	planning teams determine that they should remain in or leave a presumptively institutional setting, as well as for consumers who are determined to not have the supports they need to move to a more integrated setting. Comprehensive assessment process for all settings that provide HCBS, including residential and non-residential settings. The on-site evaluation process is a critical component of a comprehensive assessment, and cannot be administered only on a representative random sampling basis. Stakeholders must be involved in the development and implementation of the assessment process, including active and meaningful participation by consumers. This assessment process should be completed by an independent third party. If it is not completed by a third party, the process must include a system to verify the assessment tool and a sampling process
	that will test the veracity of the assessment process. Assessments must rely on information from participants and family members. Assessments that rely solely on providers will not reliable given that the focus is on the experience of the residents/participants. Any independent sampling process must be driven by, and include, input from consumers and stakeholders.
Transparency in Classification of Settings	Classification of settings as community or non-community must be transparent. Because the focus of the HCBS regulations is on the individual's experience, any appeal process for settings determined to not meet the HCBS standards must include information from the residents or participants and be sufficiently transparent so that stakeholders/HCBS participants can provide information about the setting.
Stakeholder Education	HCBS participants, family members, providers, and community members must be educated about the transition process, what is changing, and the opportunities for involvement. As the process goes on, education and opportunities for feedback must continue. Education is not

Review of Provider Policies	only for the early stages, but is critically important when the Department begins determining what needs to change and the processes developed for compliance. Review of provider policies, including enrollment and applications. All sources of standards for providers of HCBS must be evaluated for necessary changes to enforce compliance with HCBS standards. This would include administrative rules, policies, credentialing, licensing policies, required trainings, enrollment forms, compliance processes and reviews, and other provider resources. This identification process and subsequent changes should involve stakeholders.
Ongoing Monitoring and Compliance	Identification, revision, and creation of necessary policies and procedures to address monitoring and compliance during and after the transition period. Compliance with HCBS regulations will be ongoing and the Department must develop a mechanism to receive and act on complaints during the transition period itself as well as in 2019 and beyond. Participants must be able to submit complaints regarding settings, have those complaints investigated, and receive resolution of the issue where there is evidence of fundamental systemic or individual violations such as a lack of choice in roommates, access to food, schedules, visitors, or means of effective communication. This complaint process must go outside of the setting. There must also be a system that requests information regarding participant satisfaction, possibly incorporated into the person centered planning process so as to avoid conflict of interest issues and allow for an examination of other options. Compliance monitoring may incorporate provider recertification, service coordination activities, and more.
Plan for System-Wide Compliance	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.
Updates and Communication Plan	The Department should develop a communication plan that identifies stakeholders and appropriate education mechanisms to reach stakeholders. A communication plan should clearly lay out when the transition plan will be updated and that justification for changes will be provided. The Department may consider setting regular intervals for plan updates to continue stakeholder engagement.
Accessibility of Transition Planning and HCB Settings	It is critical that both the stakeholder input process be made accessible to people with sensory impairments, and that the assessment process consider accessibility (physical, sensory, and programmatic) as a key issue.