

COMMENTS REGARDING CALIFORNIA’S DRAFT HCBS STATEWIDE
TRANSITION PLAN BY JUSTICE IN AGING, NATIONAL HEALTH LAW
PROGRAM, DISABILITY RIGHTS CALIFORNIA, AND
DISABILITY RIGHTS EDUCATION AND DEFENSE FUND
September 29, 2016

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We appreciate the opportunity to review and comment on California's draft Statewide Transition Plan (STP) to comply with the federal Home and Community Based Services regulations. These regulations, which build on the decades-long paradigm shift towards the inclusion and integration of people with disabilities, will have a far-reaching and positive impact on the nature of HCBS-funded residential and day services settings. Collectively, our organizations represent a wide range of consumers and advocates who share the goal of achieving compliance with the HCBS regulations by March 2019. We have worked closely with the State as advisors, collaborators, and stakeholders and hope that these comments will be given the proper weight given our deep knowledge and expertise. We strongly believe that the comments and recommendations below will better enable the State of California to not only meet its obligations within the timeframe allowed, but also to ensure the regulations are a catalyst for positive change. We are, of course, willing and able to collaborate with the State in order to achieve this.

Our comments include a summary of concerns, and recommendations for resolving them, in the following areas:

- I. The State Should Immediately Take Action to Move Towards Compliance in the Developmental Disabilities System.
- II. The State Should Collaborate Across Departments, and Provide Necessary Resources to Achieve Compliance by March 2019.
- III. The Draft STP Misapplies the Standards for Review of Settings.
- IV. The State's Systemic Assessment is Inaccurate.
- V. The State's Process for Assessing Settings is Flawed and Inadequate.
- VI. The State has not Conducted Adequate Outreach and Education.
- VII. The State has not Set Forth a Meaningful Strategy for Ongoing Monitoring.

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VIII. The State's Service Planning Processes Do Not Meet the Federal Standards for Person-Centered Service Planning.

Each of these topics is addressed in detail below.

I. THE STATE SHOULD IMMEDIATELY TAKE ACTION TO MOVE TOWARDS COMPLIANCE IN THE DEVELOPMENTAL DISABILITIES SYSTEM

Of utmost urgency is action relating to the developmental services system. Even the state recognizes that, "California's HCBS waiver and 1915(i) State Plan program differ significantly in the populations they serve, their size and complexities, and their statutory and regulatory structures, among other differences. The largest and most complex are the DD Waiver and the 1915(i) State Plan program, where the programs serve approximately 130,000 members in the provision of a vast array of residential and nonresidential services that are separately licensed and/or regulated." (Draft STP, pp. 17-18).

In California, 24,000 adults with intellectual/developmental disabilities live in licensed community care facilities; another 86,000 live in their family homes and nearly 25,000 in independent or supported [living](#).¹ During the day, over 10,000 individuals are in Work Activity Programs and 62,000 spend their time in day and Look Alike (non-work) [programs](#).² California has 8,000 residential services providers, 2,500 day/employment providers, and 25,000 "other" [providers](#).³ With 130,000 consumers potentially affected by the HCBS rules, the sheer number of affected consumers, families, and providers necessitate immediate and aggressive steps to achieve compliance in the 2 ½ years remaining. The human and fiscal consequences of not becoming compliant by March 2019 could be disastrous.

¹ DDS Fact Book, Thirteenth Edition (2016), p. 5, http://www.dds.ca.gov/FactsStats/docs/factBook_13th.pdf. "[Return to Main Document](#)."

² Id. at p. 37. "[Return to Main Document](#)."

³ Id. at p. 39. "[Return to Main Document](#)."

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Recommendation for Developmental Services System:

The State must immediately initiate a proactive process to make the necessary legislative and regulatory changes; funding commitments; and concrete outreach, education, and assessment efforts targeted to achieving compliance by March 2019. These efforts should focus on the areas of greatest need for review based on the known characteristics of residential and non-residential settings, and include a tiered approach to identifying likely institutional settings based on known characteristics and starting to initiate compliance activities for those settings first.

**II. THE STATE SHOULD COLLABORATE ACROSS DEPARTMENTS,
AND PROVIDE NECESSARY RESOURCES TO ACHIEVE
COMPLIANCE BY MARCH 2019.**

Essential to compliance in California's complex service system is the collaboration between responsible departments. While the Draft STP refers to DSS Licensing in the stakeholder process (Draft STP, p. 18), this does not go far enough. Rather, entities such as DSS and Department of Public Health (DPH) licensing must be at the table working as partners with departments whose settings they license. It is simply not adequate for DSS and DPH licensing to provide "stakeholder input" as those entities, with the authority to promulgate and enforce regulations governing many HCB settings, are critical players in the State coming into compliance. For example, in reference to CBAS services, we note the tension between the federal HCBS rules, and the State's requirement that a CBAS center provide at least four hours of therapeutic services daily to each CBAS consumer. The State mentions the four-hour requirement in passing (CBAS Transition Plan, p. 7), but does nothing to address or even recognize this tension.

Likewise, the Department of Rehabilitation must work hand in hand with the Department of Developmental Services so that the day settings for which they are jointly responsible — and which serve tens of thousands of individuals — will be able to come into compliance by 2019.

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Essential to making the needed changes, and avoiding catastrophic loss of federal funds and/or displacement of consumers, is the need to proactively commit state resources for structural and programmatic modifications. While we commend the State for its approval of \$15 million in this year's developmental services budget for grants to providers for transitioning their programs, much more is needed. For example, programmatic changes to allow for individual choice and freedom of movement will require additional staffing in many programs. Likewise, structural changes in physical layout and availability of private spaces will also involve costs. In many instances, it is unrealistic to ask providers to come into compliance within existing resources. If the reimbursement structure is not sufficient or providers need an outlay of initial funds, the State must partner with providers to make compliance achievable.

Recommendations for State Collaboration and Commitment of Resources:

1. The STP must contain an explicit commitment from the Governor's office and/or the Health and Human Services Agency that all responsible departments, including DSS and DPH licensing, will work collaboratively, develop an action plan with timelines, and agree on strategies for the settings for which they are jointly responsible to come into compliance by 2019.
2. The State must begin now to commit the necessary resources through the state budget process to fund the structural and programmatic changes that will be required for compliance by 2019, across all affected programs.

III. THE DRAFT STP MISAPPLIES THE STANDARDS FOR REVIEW OF SETTINGS.

- A. The State must have a Mechanism to Determine whether an HCBS Consumer is Living in an Institution.

California has individuals who receive non-residential HCB services, such as day programs, while living in institutional settings. Some of these

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institutional settings are funded by Medicaid (e.g., ICF-ID/DDs); some are not. The Draft STP fails to address this issue. The STP needs to identify mechanisms to ensure that every individual who receives HCB services is living in an HCB compliant setting. This could be done by cross-checking Medicaid institutional funding with HCB funding to ensure a given Medicaid beneficiary is not receiving both HCB and institutional services. The State could also use the annual person-centered planning process to identify the person's residential situation and the characteristics of that setting.

B. The State has Submitted an Overbroad List of Settings that supposedly are Exempt from Review because they are Owned or Rented by the Consumer.

Although the State may presume that an individual living in a private house or apartment is living in a setting that meets the HCB requirements, this is only a presumption and the state must still make a final determination of compliance based on individual information about a setting. The Draft STP provides very little information about the settings the State has designated as compliant. The State's list (see Draft STP, pp. 14-15) has very broad categories, such as board and care homes, that could be anything from a small private residence in which someone rents a room, to large facilities made up of rented rooms that are very institutional settings. Regardless of size, board and care homes and other settings on the state's list of "determined compliant" settings, may have restrictive house rules that violate the HCB requirements.

The State may only presume that a setting meets the HCB requirements. The State must have a process for ensuring that none of the settings it is presuming to be compliant are actually institutional in [nature](#).⁴ For example, there may be private homes purchased to serve as "intentional" settings only for people with disabilities, which isolate HCB consumers from the larger community.

⁴ See, e.g., CMS, Delaware Approval Letter (July 14, 2016), <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/de/de-initial-approval.pdf>. ["Return to Main Document"](#)

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In addition, the State needs a method by which settings that are presumed to be compliant are tracked to ensure they remain compliant through the transition and in the [future](#).⁵ The State must verify the compliance of these settings and may do so through questions of the consumer during the person-centered planning process, information gathered during home visits by case managers, or other sources of information, such as housing inspections or abuse and neglect investigations.

C. “Choice” does not Justify a Noncompliant Setting.

In the section on private residences, the Draft STP puts undue emphasis on the assertion that the consumer chose that setting. (Draft STP, p. 15) While choice is an important part of the HCBS rules, choice does not cure a setting that is otherwise non-compliant.

In addition, this section distorts the HCBS rules by emphasizing that “[t]he settings do not restrict the member from interaction with other non-disabled people in the broader community.” (Draft STP, p. 15) The HCBS rules require that a setting support full access to the greater community — absence of restriction is not enough. For example, a setting that does not overtly restrict interaction with the broader community might not in fact meet the rules’ requirements, because of its physical distance from community activities or establishments, or programming which does not support access to the community. The same is true about the Draft STP’s other “restricts” statements, which are inconsistent with the federal rules’ requirement that a setting optimize individual autonomy and facilitate choice.

D. The Proposed Heightened Scrutiny Process is Incomplete and Unreasonable.

The State’s process for identifying settings that need to go through heightened scrutiny is incomplete and will allow many settings that should be going through heightened scrutiny to slip through. One major area of concern is that the State sets forth an incomplete idea of settings that

⁵ CMS, Delaware Approval Letter at 6. [“Return to Main Document”](#)

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isolate but sets forth very little methodology for identifying those settings. (Draft STP, p. 25) The State seems overly focused on those settings that share a building with an inpatient-services facility, or share grounds with a public institution. We see the same flaws in the CBAS Transition plan, which assumes that heightened scrutiny could apply only to one CBAS center in the state, which is on the grounds of a hospital. (Draft CBAS Transition [Plan](#), pp. 10, 23)⁶

In addition, the state's timeline for heightened scrutiny does not support gathering meaningful evidence. (Draft STP, p. 26) Importantly, the Draft STP does not include any mention of the State working to develop additional settings or how the State will come into compliance with the requirement that everyone have a choice of a non-disability specific setting.

1. The State does not adequately Describe how it will Identify Settings that Isolate.

The State fails to describe a process by which it will adequately search for and identify settings that isolate HCB consumers from the broader community. While the Draft STP describes some of the features that may help identifying a setting that isolates, such as a setting that provides multiple types of services, the Draft STP does not identify methods by which the state will find the settings that isolate. Although using provider surveys, on-site assessments, and other monitoring tools are mentioned, this is insufficient especially given that there is no information as to how the State is going to use the information.

The State should be using other methods that are outside the general assessment process to help identify settings that isolate. For example, the State could use billing information to identify settings that provide multiple HCB services such as residential and day services. The State could also

⁶ We note that the federal rules refer to being on the grounds of a "public" institution, and a hospital is not a public institution unless it is operated by a governmental entity. Thus, the State errs in focusing only on the setting that shares grounds with a hospital, and also by assuming in the first place that the automatically-isolative presumption applies to private institutions as well as public institutions. ["Return to Main Document"](#)

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use mapping and other data to determine geographic proximity of settings to one another or to institutional settings.

We recommend that the State use the methods above to identify settings that isolate, and we also ask that the State follow the examples of other states by putting groups of settings into the state's heightened scrutiny process, so that more information is gathered about these settings. The setting groups for this process would be those that are likely to isolate, or that have institutional features based on common features or the service itself, such as segregated day programs.

Tennessee, for example, is putting all of the following settings into the state's heightened scrutiny review process: Adult Day Care, Assisted Care Living Facilities, Facility-Based Day, Residential Habilitation settings where more than four persons reside, Supported Living and Residential Habilitation settings close in proximity, and Intensive Behavioral Residential [Services](#).⁷ Tennessee's stated intent in using this process is to further evaluate these settings and to "clearly identify what it believes to be appropriate and sufficient in establishing and demonstrating that the settings meet the qualities for being home and community based settings." Based on our knowledge of many settings currently funded by HCB services, we believe that certain setting types deserve this level of information-gathering and scrutiny to ensure they are actually meeting the HCB standards, whether they need to go to CMS for heightened scrutiny review, or whether consumers need to be transitioned from those settings. These setting types include work activity programs and adult development centers.

We recommend that the State take steps now to identify: licensing categories; setting types (e.g., over a certain number of beds); descriptions (e.g., located on a campus or in a cluster); and qualities (e.g., individuals spend most days with the same people in the same location) that are likely markers for settings that isolate. Such identification should be teamed with

⁷ Tennessee State Transition Plan, <http://tn.gov/assets/entities/tenncare/attachments/TNProposedAmendedStatewideTransitionPlanCV.pdf> (received final approval from CMS). "[Return to Main Document](#)"

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subsequent assessment of those settings and, as appropriate, assistance to providers so that they can achieve compliance, through redesign of their programs or otherwise.

Many residential and non-residential settings in California are presumed institutional, based on the CMS guidance. Some of these settings will not pass the heightened scrutiny test, nor should they. California's Draft STP, however, fails to identify such settings, or categories of such settings, and fails to identify how and when the State intends to do so.

The HCBS regulations present an opportunity for California to modernize its residential and non-residential service system, to comply with the HCBS regulations, avoid risking loss of significant federal funds, and most importantly, improve the lives of the Californians with disabilities, including older Californians, whom it serves.

2. The State Misstates the Heightened Scrutiny Process.
(Draft STP, pp. 25-26)

For heightened scrutiny determinations, the State wrongly says that it automatically will pass on information from the provider to CMS. This is incorrect. The State must recognize its responsibility to put forth for heightened scrutiny only those settings it thinks meets the community characteristics requirement.

To ensure state compliance with the rules, the State should work with providers to achieve compliance, but not allow final decisions to be [appealable](#).⁸ If, however, a provider appeal process were included, a decision favorable to the provider should not limit either the State's obligation to refer the heightened scrutiny determination to CMS, or CMS's obligation to make an independent determination as to whether the setting had overcome the presumption of being likely isolative.

⁸ See, e.g., Kentucky STP, p. 68, http://www.chfs.ky.gov/NR/rdonlyres/C11A01F5-6378-45DA-B17B-FF7B26B67E26/0/KYStatewideTransitionPlanFINAL_2015.pdf (initial approval received from CMS). The Kentucky STP states: "The determination of a compliance level is not one of the actions that can be appealed." ["Return to Main Document"](#)

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The State also has a responsibility to ensure that there is sufficient and appropriate information being submitted to CMS. The types of evidence listed in the Draft STP (p. 25) for heightened scrutiny do not fully reflect the suggestions in CMS [guidance](#).⁹ Licensure and employee requirements do not show that the setting meets the HCBS standards for community access. What is needed is information that shows how the setting facilitates access to the community. Similarly, proximity to transportation is not enough; other factors, including adequate support for the consumer, will determine if the consumer realistically can use the transportation to access the community.

3. The Draft STP does not provide for Adequate Time for Public Input on Heightened Scrutiny Determinations.

The turnaround time from when a setting is identified for the heightened scrutiny process, to when evidence is submitted, is likely too quick to develop solid, specific evidence on a setting. (See Draft STP, p. 26) This information should include public feedback, which usually requires at least 30 days.

It seems that the State is contemplating soliciting information on individual settings regarding heightened scrutiny determinations. Public comment is unlikely through that strategy. The State instead should identify all the settings that have been determined to possibly need to go through heightened scrutiny and initiate a public comment process on those settings. This will allow joint consideration of certain types of settings, which will lead to greater consistency. The State should also solicit public comment on final determinations.

4. The Draft STP Misstates the Rules. (Draft STP, p. 6)

The Draft STP misstates the federal rules relating to modification of the standards. The Draft STP says that all standards can be modified through

⁹ CMS, FAQ Heightened Scrutiny Process, pp. 2-4, <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/home-and-community-based-setting-requirements.pdf>. ["Return to Main Document."](#)

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the person-centered service plan (Draft STP, p. 6), but such modification is only authorized in the rules for the standards relating to provider-owned or controlled settings. 42 C.F.R. § 441.301(c)(4)(vi)(F).

Also, pursuant to the rules, person-centered planning cannot modify a person's right to a setting that is physically accessible to him or her. It should be noted the Draft STP's requirement that a setting be "physically accessible" (p. 6) is not equivalent to the requirement in the federal rules that the "setting is physically accessible to the individual." 42 C.F.R. § 441.301(c)(4)(vi)(E). Physical accessibility for an individual is based on his or her needs; meeting ADA Accessibility Guidelines or building codes may be insufficient to ensure that an individual is actually able to use the bathroom, the kitchen, or even his/her designated bedroom.

The Draft STP also lists who would be present in a person-centered planning meeting. (Draft STP, p. 27) Under the relevant federal rules, however, the meeting's participants are chosen by the consumer. 42 C.F.R. § 441.301(c)(1).

Recommendations for Review of Settings:

- 1) The State must establish mechanisms to determine if HCBS consumers are residing in institutions. Some HCBS consumers are residing in institutions, but receiving HCBS services outside those institutions.
- 2) The State must revise its procedures so that it does not inappropriately deem certain settings compliant just because those settings are owned or rented by the consumer.
- 3) The State must revise its procedures so that it is able to identify settings that are likely to isolate. Currently, the State is almost exclusively focused on those settings that share a building with an in-patient services institution, or share grounds with a public institution.

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- 4) The State should submit settings to CMS for heightened scrutiny review only if the State first has determined that the setting has overcome the presumption of institutional qualities.
- 5) The State should solicit comment from the public on the State's determination on whether a setting has overcome a presumption of having institutional qualities.

IV. THE STATE'S SYSTEMIC ASSESSMENT IS INACCURATE.

- A. Contrary to the Draft STP's Assertions, California's Laws and Regulations do not Establish Compliance with the HCBS Rules. (Draft STP, Appendix B, Systemic Assessment Summary)

The Systemic Assessment Summary appears to be intended to justify inaction, rather than the urgent action that is needed. The State claims that the Systemic Assessment Summary is "an indication of compliance." (Draft STP, Appendix B., p. 35) This claim is not true.

While the cited statutes and regulations are not necessarily in conflict with HCBS requirements, they certainly do not establish that HCBS requirements have been met. For example, as to Residential Care Facilities for the Elderly (RCFEs), the one statutory reference (Health and Safety Code section 1569.269) contains a long list of important, but not necessarily relevant, resident rights. Some rights have a relationship to the HCBS requirements, but they do not require nor measure compliance and cannot therefore represent that the requirements are "met" by the current governing authority. The cited state regulations suffer from the same problem. For example:

- Section 1569.269(a)(8) and (26) require that residents be able "to make choices concerning their daily life in the facility" and "be encouraged to maintain and develop their fullest potential for independent living through participation in activities that are designed and implemented for this purpose." Neither these provisions nor any others require the integration necessary under

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Federal Compliance Category No. 1 (being integrated in and supporting full access to the greater community).

- The regulatory cites listed for Federal Compliance Category No. 2 (22 Cal. Code Regs. §§ 87464, 87467, and 87468) are silent as to “Giving individuals the right to select from among various setting options, including non-disability specific settings and an option for a private unit in a residential setting.”
- Federal Compliance Category No. 10, requiring a physically accessible setting, is not “met” by the cited regulations (22 Cal. Code Regs. §§ 87219, 87307, and 87705). At best, these regulations are silent on accessibility or only partially meet the federal requirement. And, of course, the existence of these regulations does not indicate that RCFEs actually are in compliance.

We note that the Systemic Assessment sometimes cites waiver language as evidence that the requirement has been met, or proposes modification of waiver language as a remedial strategy. We understand that CMS does not accept waiver language as indication that a state’s laws are in compliance, and for good reason. A waiver is an agreement between a state and the federal government, and is not designed for enforcement against a provider.

Also, the Systemic Assessment Summary ignores setting characteristics that may indicate whether the setting is in compliance. Such characteristics include the number of residents, the configuration/location of residences, and the community integration opportunities offered. For example, residential settings such as Adult Residential Facilities, Group Homes, and RCFEs might have as few as two residents or more than 100; some residential and non-residential settings have delayed egress and/or secured perimeters; and some "day type services" and Work Activity Programs include community-based activities for consumers, and some do not. We note that cited RCFE regulations assume that some facilities will house more than 50 residents, and a setting of such size will undoubtedly

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have institutional qualities. (Draft STP, Appendix B, pp. 63-65, citing to 22 Cal. Code Regs. §§ 87219 and 87555).

Finally, the State's remedial strategies are generally inadequate. One suggested remedy from the State is a modification of waiver language (Draft STP, Appendix B, pp 56, 58-59), but, as discussed above, waiver language generally cannot be enforced against providers. Furthermore, the State's remedial strategies do not commit State funding and do not provide realistic timelines to ensure that necessary legislative and regulatory changes will be approved and implemented by March 2019.

We note that we see some comparable issues in the State's Draft CBAS Transition Plan. (Draft CBAS Transition Plan, pp. 16-18; Appendix III, pp. 1-5).

B. The State Fails to Acknowledge the Scope of Change Necessary to bring Work Activity Programs into Compliance.
(Draft STP, Appendix B, p. 66)

The State properly identifies Welfare and Institutions Code section 4851, regarding Work Activity Programs, as conflicting with Federal Compliance Category No. 1, the requirement of: "Being integrated in and supporting full access to the greater community, including opportunities to seek employment and work in competitive integrated settings" Section 4851(e) states: "Work activity program includes, but is not limited to, sheltered workshops or work activity centers, or community-based work activity programs...." The state's proposed remedial strategy is to modify statutes and/or regulations as needed to "align with federal requirements" by the fourth quarter of 2018.

The State's proposed schedule fails to recognize that many work activity programs may need to be wholly or significantly redesigned or dismantled to come into compliance. Given the approximately 10,000 individuals in Work Activity Programs, the State's proposed statutory and regulatory "alignment." just months before the March 2019 deadline, and without any identified commitment of resources, falls far short of what is needed to produce timely compliance.

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Recommendations for Systemic Assessments:

The State should re-do the Systemic Assessment with a more honest consideration of whether existing laws and regulations (not including waiver documents) are adequate to establish and maintain compliance with the federal HCBS rules. The current Systemic Assessment is not useful, since it too easily comes to the inaccurate conclusion that the existing statutory and regulatory scheme is adequate to guarantee compliance with the HCBS rules. The Assessment also wrongly interprets silence on an HCBS requirement as compliance. It is critically important that existing laws and policies reflect all the requirements of the HCBS rules. Currently, many HCBS consumers in California live and/or receive services in institution-like environments. It is unrealistic and unhelpful to pretend that California law already contains the HCBS requirements. As to sheltered workshops, the State must immediately undertake a public policy approach to dismantling or converting these programs, as other states have done.

**V. THE STATE'S PROCESS FOR ASSESSING SETTINGS IS
FLAWED AND INADEQUATE.**

On June 30, 2015, Disability Rights California (DRC), the National Health Law Program, Justice in Aging, and the Disability Rights Education and Defense Fund (DREDF) submitted comments on the state's draft assessment and survey tools. Those comments included recommendations regarding the tools themselves, and about the process through which providers and consumers would evaluate settings. While we appreciate the additional information provided in the Draft STP (pp. 21-25), many of those earlier comments still apply, and we attach and reiterate them here.

A. Survey Tools Are Likely to Elicit Pro Forma "Yes" Answers.

One principal problem is the inadequacy of the State's survey documents. In general, the survey documents are not focused enough to distinguish between situations where integration with the community is real, and situations where integration is possible but unlikely.

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Consider, for example, Attachment IV, the Provider Self-Survey for Residential HCBS settings. Access to the community is addressed primarily through the following three [questions](#) (p. 3):¹⁰

- Do the residents have the freedom to move about inside and outside the home or are they primarily restricted to one room or area?
- Do residents regularly receive information regarding services in the broader community and access options, such as public bus/light rail, taxi/van services, special transportation providers, etc.?
- Does the home utilize access to the community as part of its plan for services?

As these questions are written, the provider could honestly answer “yes” to each, even if consumers rarely if ever leave the setting. These questions specifically, and the survey document more generally, do not address the basic problem. The problem in most cases is *not* that residents are formally prohibited from leaving. Instead, they theoretically could leave, but the provider does not offer adequate support and does not prioritize community access.

We recognize that the third question inquires into whether the provider utilizes community access in its service plan, and then asks for an explanation. Theoretically, a provider could give a lengthy explanation, and the State could closely evaluate whether the explanation is an adequate indication of community access. We believe that that scenario is unlikely. Much more likely is the possibility that the provider will answer “yes” and offer a limited explanation, and the State without much consideration will approve the setting as compliant.

This problem is not limited to this particular set of survey questions. The survey document often asks general questions that can be easily be

¹⁰ A fourth question inquires into consumers' opportunities to seek employment in integrated settings. [“Return to Main Document”](#)

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answered in the affirmative, and then also asks for an explanation. Proper implementation of the federal regulations would require careful, individualized consideration of each explanation, but we believe such individualized attention is unlikely under the proposed system.

If the surveys are to be useful, they must ask questions that are detailed enough to assess a setting's level of integration. If the surveys rely heavily on a narrative explanation of a "yes" or "no" answer, too much discretion is given to the person reviewing the survey, which probably will lead to "yes" answers routinely being accepted as an indication that the setting meets federal standards.

We note that this inadequacy also impacts the State's Draft CBAS Transition Plan. (pp. 20-21)

B. The Process for the Provider Self-Survey is Flawed.

It does not appear that completion of the surveys is mandatory, or that providers will experience consequences for failure to return the surveys. Voluntary compliance will only incentivize non-compliant providers to choose not to respond. We repeat the recommendation from the 2015 comments that California follow the lead of other states and make the provider self-survey mandatory.

The STP also does not identify any method of validation, which is critical to making the provider self-survey meaningful. Validation should be multi-tiered, and include linking the provider self-survey to a consumer self-survey (see below), and cross-validation with the on-site assessment. This is particularly important when provider self-survey questions ask for the existence of, for example, policies regarding consumer choice and privacy, but not for information about the content of those policies or copies of them.

Relying on "program staff, or care coordination agencies and regional centers" (Draft STP, p. 22) to analyze survey results will necessitate guidance and training, as well as cross-checking to ensure consistency in results. We strongly encourage consumer participation in the analysis of provider self-surveys.

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In addition, provider survey trainings should not simply tell providers how to fill out the survey to avoid further investigation, but should educate them about HCBS requirements and how to achieve compliance.

Finally, we note that the Draft STP requires corrective action, rather than on-site assessments, if a setting needs “relatively straightforward corrective action” such as staff training or additional documentation. The category of “relatively straightforward corrective action” is a broad and ambiguous category that may lead to insufficient on-site assessments and similarly insufficient validations.

C. The Proposed “Member” Survey has had Insufficient Consumer Input.

In late 2015, DRC, DREDF, and Justice in Aging were asked to, and did, participate in a meeting with state staff to discuss a “beneficiary self-survey.” We strongly encouraged the State to include consumers of HCBS services to participate in the development of consumer self-survey tools and processes. To our knowledge, there has been no further communication or inclusion of advocates or consumers in that process. The STP also does not include a beneficiary assessment tool, or any piece of such tool. We are thus confused by the representation that core questions have been developed and that an agreed-upon process is in place. (See Draft STP, p. 23)

We have grave concerns about a consumer assessment process going forward without the active participation of consumers and advocates in its development and implementation. We have no idea how the State intends to conduct “surveys of members [which] will pose non-threatening questions to effectively elicit members’ thoughts and feelings about the HCBS they receive, their ability to actively participate in life decision making, and any problems they encounter” and, in the absence of any shared tools or processes, how the State can possibly achieve this. (Draft STP, p. 22)

The member surveys will ask about consumers’ “ability to actively participate in life decision making,” demonstrating that the State slightly

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misunderstands the rules. (See Draft STP, p. 22) This approach focuses on the wrong thing — the consumers' "ability" — instead of whether the setting facilitates and supports integration in the greater community. It is positive, however, that the state intends that surveys be tailored to different populations. (Draft STP, pp. 22-23)

As to the stated intent to add core questions to regularly scheduled assessments or reassessments (Draft STP, p. 23), such processes must: a) include the consumer; b) be conducive to the consumer actively participating; and c) be conducted so as to elicit the needed information. It is our experience that many HCBS programs either do not have an assessment or reassessment process, or that such processes may not be appropriate for this function. For example, regional center annual Individual Program Planning meetings vary widely in the degree to which consumers are actively involved, if at all. Moreover, the pressure to discuss needed services and supports may make it impossible to leave enough time or opportunity for consumers to understand, let alone respond to, the "core questions."

It is critical that survey processes elicit information from the consumer, and not his or her authorized representative, whenever possible. Finally, it is important that surveys indicate whether information to answer the question was from the interview or from observation, and whether the responder was the consumer or the authorized representative. We strongly encourage the state to convene focus groups, led by and/or with robust consumer involvement, to educate and elicit input from consumers in a variety of settings.

Finally, we are troubled that the focus will be only on the provider with whom the consumer resides or spends the most time. (Draft STP, p. 23) This approach, while perhaps expedient, significantly undermines the assessment process. Many individuals, including regional center consumers, reside in provider-owned or controlled HCB settings, and also spend their days in settings owned or controlled by another provider. There is no justification for failing to assess whether a consumer's daytime setting is compliant or not. Likewise, consistent with our comments

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regarding "private residences," both the home and day settings should be part of the compliance review.

D. The State has Provided Insufficient Information regarding On-Site Assessments.

More information is needed about the on-site assessment process and compliance procedures, including the size and composition of "statistically valid samples," the timeframe and protocols for conducting assessments, and the inclusion of presumed institutional settings other than those in proximity to institutions. (Draft STP, pp. 23-24) We are troubled that the on-site assessments do not appear to contemplate inclusion of consumers or advocates.

To the extent that the on-site reviews are rigorous, independent, and transparent, and involve consumer advocacy organizations and beneficiaries, this approach is potentially effective. However, many details of the on-site review are lacking in this STP. The State has not indicated how it will select a truly representative sample of sites within each class for on-site review, how big that sample will be, or what constitutes the threshold for a "pattern of non-compliance." (Draft STP, p. 24)

Overall, we have serious concerns that, based on the information in this draft, the on-site review process does not appear to be robust or have sufficient protections to ensure its independence.

E. The Draft STP does not Adequately Describe a Strategy for Follow-Up when a Setting is Assessed to be out of Compliance.

The Draft STP suggests that follow up of compliance issues will be the responsibility of the administering State department or entity but does not describe how follow-up compliance will be established. (Draft STP, p. 24) Will this be another onsite assessment? Or will compliance be assumed through a phone call or promise from the provider that things have changed? There needs to be a way to validate that the provider has changed and is now compliant. Moreover, there is no indication that the State has or will commit resources for providers to complete remedial

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actions, nor any indication that the on-site assessments and compliance determinations will be done sufficiently in advance of March 2019 so that providers will have the opportunity to take remedial actions.

Recommendations for Assessment of Settings:

- 1) The State should compare provider self-assessment results against the findings from a representative sample of settings that undergo robust, independent on-site review.
- 2) The State should develop the consumer “core questions”, surveys, and/or assessment processes (including focus groups) in conjunction with consumers.
- 3) The State should link the results from the beneficiary assessment survey directly to results from all their associated providers. This would allow the state to use the results from the beneficiary surveys to cross-check provider responses. Michigan is currently piloting such an approach and includes details on that approach on its HCBS transition website.
- 4) Along with developing a valid and reliable mechanism to verify the provider self-assessment results, the State should clarify its process for resolving discrepancies. We applaud California for including a trigger whereby if the provider self-assessments results reveal systematic bias, an expanded review may be triggered. But if the state does not adequately validate the provider self-assessments, there will be no way to reliably know if patterns of non-compliance exist.
- 5) The STP should guarantee that representatives of consumer advocacy organizations be part of the on-site survey team or at least be directly consulted as part of the review process.
- 6) The State should follow a more thorough process that establishes training and qualification standards for on-site reviewers; includes reliability tests to ensure consistency in results; sets process requirements to interview beneficiaries

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chosen by reviewers and not in the presence of provider staff; ,
consults with consumer advocacy groups who are familiar with
the setting; and requires transparent reporting of results.

- 7) Certain types of providers that the State can already identify as likely needing to substantially change their business model to comply, such as sheltered workshops, should receive more focus from on-site reviews, including a larger sample size from the beginning. Relying solely on self-assessment results to flag problem providers is not sufficient, especially if the self-assessment tools have not been properly validated and vetted for accuracy and reliability.

**VI. THE STATE HAS NOT CONDUCTED ADEQUATE OUTREACH
AND EDUCATION.**

The Draft STP (p. 20) alludes to the “important early step” of providing all affected parties with information and education on the requirements of the HCB setting requirement “on a continuous and ongoing basis.” We agree with this goal, but do not agree that it has been met. General public interest notices and meetings on the STP’s development were posted in Spring 2014 in the California Regulatory Notice Register, which cannot be considered a tool of general public education, particularly for HCBS consumers and their families. DHCS posted its first STP draft and its second STP draft about 6 weeks apart in Fall 2014. Over half a year later, DHCS posted a “general public interest notice” informing stakeholders of a conference call in July 2015 to discuss the revised STP and comments received on its draft On-Site Assessment Tools and Provider Self-Survey Tools. Individual state departments who administer HCB programs sent some additional notice. The characterization of these sporadic public interfaces as continuous ongoing education efforts, particularly in regard to HCBS consumers, is an overstatement at best.

Also, public comment procedures are not accessible enough. Comments on the STP generally must be written and submitted through postal or electronic mail. Moreover, the State currently states that public comments “should be submitted via the STP Public Comment Template.” This

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statement does not match with the State's expressed desire for "inclusive stakeholder processes," or with the State's endorsement of the need for consumers' input on how they experience community inclusion and freedom of choice. Consumers with disabilities, and those who are potentially lower income and therefore particularly dependent on HCB settings, are likely to find it difficult to comment on a template. The request presupposes having a computer or other device for the person's own independent and secure use, and software that is capable of downloading the template, filling it out, and returning it as an email attachment or through the mail (which then requires printing equipment). The situation is further complicated for any consumer who is visually impaired or blind and uses screen reading software.

A comment template is convenient for the State. For the public and for HCBS consumers, however, the template is both off-putting and offers technical difficulties of use and navigability. Other states have incorporated strategies such as taking public comment via phone or message line, which reaches consumers who can express their individual concerns but may face barriers to successfully sending private item communications.

On education, the State's draft STP fails to specify how the State plans to educate consumers on their rights. In the almost two years since the State first introduced a STP, we are aware of few concrete plans for how the State will ensure consumer education on their rights under HCB rules, on what community access looks like, and the potential personal impact of transition. The Draft STP emphasizes education for providers, but pays only lip service to consumer education. In Oregon, by contrast, the state provided their proposed transition plan to the Department of Intellectual and Developmental Disabilities and the state's three contracted managed care organizations (MCOs) with a request to share the plan not only with their provider networks, but also with individual consumers and their families. CDA has made specific efforts to reach CBAS consumers, but DHCS and other departments do not appear to have plans to provide similar outreach.

In reference to *provider* education, the State seems to be behind the level of education provided in other states. DHCS is making attempts to provide

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information to providers, but does not seem to have reached the detailed level of training seen in some other states. In Oregon, there are specific provider curricula on individual rights, protections, person-centered thinking, and community inclusion. Washington's provider training specifically addresses the consumer's right to freedom of choice and its applicability to the consumer's activities, schedules, appearances, and services. Washington has also specified that this training is needed for providers across settings and operating agencies.

CMS feedback to other states has pointed out that providers lacked sufficient understanding of individual rights and privacy, had not effectively implemented policies to recognize and safeguard individual rights, and had not provided much training for people who can significantly impact consumers' experience of rights, such as provider volunteers. These are all aspects of provider training that can and should be addressed in California's STP.

Recommendations for Outreach and Education:

The State should expand its ability to accept comments from consumers, instead of relying so heavily on a comment template. Regarding education, the Draft STP should be revised to provide more detail on education for consumers and providers. Such training should include meaningful curricula on the HCBS rules.

VII. THE STATE HAS NOT SET FORTH A MEANINGFUL STRATEGY FOR ONGOING MONITORING.

A. The State's Plans for Monitoring are Hampered by Ineffective Survey Documents.

Effective monitoring is an absolute necessity if the HCBS settings requirements are to meaningfully improve quality of life for California's HCBS consumers. Reaching compliance in March 2019 is only an initial step: the real test will be to maintain compliance through 2019 and future years.

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The State's monitoring plans are laid out in in various sections of the Draft STP, including a discussion of "Compliance Monitoring" on page 29, and detailed information on the Setting Assessment Process as set forth in Attachment VI. On the surface, these plans contain significant detail, but we find the monitoring plans in substance to be less than meets the eye. The main problem is the inadequacy of the survey documents, as discussed earlier in this letter. The surveys are designed in a way that is likely to elicit many "yes" answers, leading in turn to rote determinations that a setting is in compliance, even when (for example) consumers have little or no practical access to the greater community.

B. The State has Failed to Identify Adequate Complaint Handling Processes.

As a practical matter, the efficacy of monitoring will depend on the State's ability to accept and resolve complaints. The State's Setting Assessment Process (Attachment VI) calls for site visits annually or every other year, depending on the program. Needless to say, individual consumers should not have to wait months and months for a problem to be addressed, and must have access to a complaint system that effectively resolves complaints in a timely matter.

The Draft Transition Plan, unfortunately, offers little detail. The topic of complaints is raised on pages 18, 23, and 24, but without an explanation as to how complaints would be handled. Page 18 refers to "expanding existing complaint and appeal processes," but without identifying those supposedly "existing ... processes."

This topic needs additional explanation at this stage — at a minimum, the state should identify the "existing ... processes" on which it is relying. Existing processes are wholly inadequate; to prove otherwise, or to better identify necessary improvements, the State should revise the Draft Transition Plan to describe the complaint and appeal processes that it believes are relevant to assessment and ongoing monitoring.

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Recommendations for Monitoring:

The State should revise its survey documents so that they will better identify settings that isolate consumers. The State also should revise the STP to explain the complaint processes that will be available.

VIII. The State's Service Planning Processes do not meet the Federal Standards for Person-Centered Service Planning.

The Draft STP relies to a great extent on service planning and the person-centered [service plan](#).¹¹ Person-centered service planning is required and governed by federal regulations that have been effective since [March 2014](#).¹²

We understand that CMS has directed states not to include service planning processes as part of a state's transition plan, since the service planning rules have been effective since they became final in March 2014, with no transition period allowed. However, California's service planning processes are *not* in compliance with federal regulations, and are *not* adequate to handle the individualized determinations contemplated by the Draft Transition Plan.

For example, enclosed with this letter are two Individual Service Plans (ISP) from the Assisted Living Waiver Program. One of these ISPs was created with the current form which, as indicated in the form's footer, was updated in November 2015. The other ISP was created with the previous form. In each case, beneficiary-identifying information has been redacted.

Although each form concerns a different resident, the language used in the forms is frequently identical. Both the predecessor form and the current form, for example, address anxiety, the risk of falls, impaired skin integrity, and the need for care coordination: in each case, the intervention/goal/outcome is word-for-word identical:

¹¹ See, e.g., Draft STP, p. 6 (authorizing modification of HCBS settings requirements through the "person-centered service plan"). ["Return to Main Document"](#)

¹² See 42 C.F.R. § 441.301(c)(1)-(2). ["Return to Main Document"](#)

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Anxiety: "Support client by assisting with activities/medications designed to prevent further complications. Prevent behavior that could contribute to mental health exacerbation. Compliance with medications, emotional stability, and engaged in supportive behavior."

Risk of Falls: "Supervision of medications, safety of environment, and use of appropriate personal devices. Identify issues that could impair ability to avoid falls. No falls reported."

Impaired Skin Integrity: "Implement turning, repositioning schedule. Utilize pressure relieving devices. Apply dressings as ordered. Resolution of compromised areas, no further damage acquired. Skin will be intact, no erythema noted on assessment."

Care Coordination: "CCA [Care Coordination Agency] will visit at least one time per month to monitor and ensure quality and coordination of care. Ensure that appropriate support is being provided and needs are met. Appropriate support identified and no unmet [needs](#)."¹³

Simply put, there is nothing in these ISPs that suggests any meaningful input from the resident or the resident's representative or friend. Rather, these ISPs were developed by the care coordinator through a computerized protocol that generated specified interventions and goals depending on the diagnosis/problem/concern identified through assessments.

We note that the current ISP includes the following language: "By signing below, the beneficiary and/or responsible party agree that he/she has been an active participant in the development of the plan and has received a copy of the plan." The beneficiary then is given yes/no choices as to whether he or she has "been an active client in the development of this service plan," agrees with the entire ISP, and/or disagrees with part of the

¹³ Predecessor ISP at 1-2; Current ISP at 2. ["Return to Main Document"](#)

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ISP. This language clearly has been designed to demonstrate compliance with the federal person-centered planning rules, but we contend that these pro forma assurances cannot rescue an ISP that otherwise shows little or no signs of consumer involvement.

In addition, we note that the process focuses on why a person is restricted from doing things, or on medical care, as opposed to how services and settings recognize a person's strengths and weaknesses in order to facilitate a person's access to the community. While, under the federal rules, a service plan needs to document any changes to the requirements, the State's current process for most HCBS consumers focuses on why they cannot do certain things as opposed to how a setting addresses needs and helps the person access the community. The focus of this "person centered planning" is on protection rather than integration and on negatives as opposed to positives. The State's approach to planning needs to change to better facilitate community access.

The inadequacies of the planning process for assisted living services indicate that the State and CMS should not assume that all service planning is already in compliance with federal rules. Instead, the State and CMS should take a hard and honest look at all HCBS service planning processes, and revise the processes so that ISPs truly reflect a beneficiary's individual preferences. Otherwise, the Draft Transition Plan's reliance on person-centered planning is wholly misplaced and does a great disservice to HCBS consumers.

Similarly, the Individual Program Planning (IPP) process mandated by the Lanterman Act for regional center consumers differs significantly from the person-centered planning (PCP) requirements in the federal rules. For example, the IPP is required to be "centered on" the consumer, not "driven by" the [consumer](#).¹⁴ The PCP includes people chosen by the consumer; the IPP does not require that the consumer even attend the meeting and parents and conservators must be permitted to [participate](#).¹⁵ Even when implemented in accordance with state law, the IPP in practice is about

¹⁴ Welfare and Institutions Code section 4646(a). ["Return to Main Document"](#)

¹⁵ Welfare and Institutions Code sections 4646(b) and (c). ["Return to Main Document"](#)

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discussion of and authorization for services. The IPP process should be informed by person-centered planning, but it cannot substitute for it.

We note that the State recently released a draft of the Individual Plan of Care (IPCO) for CBAS. We commend the state and stakeholders for a meaningful and transparent process of developing this draft, which holds promise for true person-centered planning. Once that draft is finalized, its success will depend to a great extent, however, on how the State, through training and otherwise, implements the form. The format is only a start — the new form will serve its purpose only if care coordinators, service providers, and consumers all approach service planning with adequate education and preparation.

Recommendations for Person-Centered Service Planning:

Given the importance of service planning in the HCBS rules, CMS should review the State's service planning procedures across all programs and settings. CMS should require the State to revise those procedures so that they are in compliance with the federal person-centered service planning rules. The State should also be required to revise and provide funding for the processes for service planning as needed to focus on how a setting will facilitate access to the community as opposed to justifying restrictions.