Nothing about us without us!

December 8, 2014

Department of Health Care Services
Long-Term Care Division, STP comments
1501 Capitol Avenue, MS 4503
PO Box 997437
Sacramento, CA 95899-7437
VIA EMAIL: STP@dhcs.ca.gov

Dear Sir or Madam:

The Autistic Self Advocacy Network (ASAN) appreciates the opportunity to submit the following comments on California's statewide home and community-based services (HCBS) transition plan.

Outreach to Stakeholders

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 is 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.

According to CMS, there are two steps to the state transition plan process. First, the state must look at its current HCBS program and determine which aspects of the program are or are not in compliance with the new rule. Second, the state must submit a full transition plan explaining how it will bring its programs into full compliance.[1] In its recent guidance, CMS explained that the public must be able to comment at both steps of the process.

After reviewing the November 7 transition plan, we conclude that it is, at this point, primarily a proposal to assess the Department's existing programs and develop a draft plan in the future. Although the plan discusses opportunities for public comment during

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[1] Centers for Medicare and Medicaid Services, Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Setting Requirements (Sept. 5, 2014), available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Statewide-Transition-Plan-Toolkit-.pdf.

the assessment process, it is critical that you also offer the public the opportunity to comment on the final transition plan.

It is also important that you develop a plan to engage stakeholders, especially self-advocates and self-advocacy groups, in the assessment process. The Department of Health Care Services 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. All assessment teams that are described in the draft transition plan must include consumer representation and meaningful consumer participation. The Department may consider setting regular intervals for plan updates to continue stakeholder engagement. Otherwise, the opportunities for public input on changes to HCBS programs cannot 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.[2]

As the state develops the draft transition plan, we have several recommendations for seeking stakeholder feedback. First, it is critical that both the stakeholder input process be made accessible to people with sensory impairments, and that the assessment process consider accessibility (cognitive, physical, sensory, and programmatic) as a key issue. 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. Consumers may also be unable to travel to regional meetings. We suggest that the Department actively reach out to consumers for feedback, including by visiting consumers where they live and work.

The Department should 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 should be a 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.

Some stakeholder outreach activities, such as assessments of providers, may require not only outreach to consumers but active feedback loops that allow continuous involvement throughout the assessment process. 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.

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[2] 42 C.F.R. § 441.304(f)(1), as amended by the new rules set forth at 79 Fed. Reg. 2947, 3032 (Jan. 16, 2014).

The Department should also, as part of the assessment process, 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.

Assess specific providers and practices.

The November 7 transition plan proposes to assess various categories of service provider, including group homes, work activity programs, adult residential facilities, and adult day care facilities. Although assessing settings by category will be useful, it is crucial that California also assess individual settings within these categories to determine whether they meet the new HCBS criteria. This process must include on-site evaluations of specific providers, 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 and participants. Any independent sampling process must be driven by, and include, input from consumers and stakeholders.

In the early stages of the assessment process, California should identify HCBS providers to be evaluated, along with both site information and the category of service provided. Provided to the public, this information will allow the Department to gather information about the 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 *either* to meet or not to 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.

California should pay particular attention to settings, such as gated communities, that CMS has found are highly likely to have the characteristics of an institution. California is home to numerous such settings, such as Sweetwater Spectrum or Golden Heart Ranch,

in which resident housing is clustered at a specific site along with "co-located and operationally related"[3] programs such as ranches, farms, and social or recreational activities. Although other settings may be able to change their service model to comply with the new rule, it is unlikely that residential settings that are designed to cluster people with disabilities will be able to come into compliance without major architectural changes. California must develop a plan either to ensure that residents in these settings have a plan in place to transfer to more integrated settings. It should be noted that formal separation of the real estate and service-provision components of such clustered settings should not be sufficient to meet the requirements of the rule, as the fundamental nature of the setting would remain unchanged.

The transition process must ensure that individuals are included in the community not just in terms of where they live, but also how they spend their day. Right now many people are receiving group-based day services that are not really integrated. Recipients spend most of the day at a center that only serves people with disabilities. When they go out on trips "into the community," they are in big groups and have limited opportunities to interact with people outside of the group.

"Work Activity Programs," which are set in sheltered workshops, are also an example of day services that aren't integrated. In sheltered workshops, people with disabilities all work together – the only people without disabilities are supervisors and service workers. In work crew arrangements, people might be working in the same building as nondisabled people but they are still isolated because everyone on the work crew has a disability. Sheltered workshops and work crews also usually pay less than the minimum wage. Instead of funding these kinds of job placements, California should ensure that individuals have access to supported employment services that help people find and keep real jobs that pay real wages. People should be working either independently or alongside coworkers who don't have disabilities. Many states, like Rhode Island, are already moving people out of sheltered workshops and into integrated employment.

Develop Capacity to Transition Individuals Currently in Segregated Settings

We are concerned that, although California proposes to assess settings, such as gated communities and intermediate care facilities for people with developmental disabilities, that are "presumed to not have the qualities of HCBS,"[4] the transition plan states that "California does not anticipate that relocation of consumers will be necessary, unless identified on an individual basis through the person-centered planning process." CMS has made clear, however, that it is highly unlikely that services in these settings will be eligible for HCBS funding under the new rule.

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[3] Centers for Medicare and Medicaid Services, *Guidance on Settings that Have the Effect of Isolating Individuals Receiving HCBS from the Larger Community* (2014), available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf.

[4] 79 Fed. Reg. 2947, 2968 (Jan. 16, 2014).

It is imperative that California take steps, before the completion of the assessment process, to increase availability of services in integrated settings such as scattered-site supported housing, shared living, and supported employment, including services for people with significant and complex needs. These models best allow for integration into the community as required by the new rule. We note that California is preparing to introduce a new self-directed services option for people with intellectual and developmental disabilities. This program can be used to expand access to supported housing and employment.

It is highly important that these services be in place and ready to accept new clients as soon as possible, to accommodate individuals currently receiving services in settings that do not meet the standards of the new rule. The plan should include quantitative benchmarks for development of new services – including expansion of self-directed services programs – across the five-year transition period; an explanation of the rate-setting process to ensure adequate provider networks; and, where necessary, a discussion of funding sources (such as HUD or state funds) to ensure an adequate array of affordable, scattered-site housing options for HCBS recipients.
In order to minimize the number of individuals who will have to transition to new settings at the end of the assessment process, it is important that California stop new placements into settings that are unlikely to meet the standards of the new rule, such as clustered and congregate projects, gated communities, residential facilities, and ICFs. California should reject applications for new clustered and congregate projects.

California must not only increase availability of integrated non-residential settings as well as residential ones. Instead of funding center-based day services, California must offer individual day services that let people with disabilities participate in the community on their own terms. For example, a person might need transportation support and a personal attendant to help them find their way around the community. People should be able to choose activities that they want to do, not just options on a list. They should have the support that they need to visit our friends and relatives, join clubs, volunteer, or find a job.

Finally, the plan should ensure that HCBS recipients – particularly those living in non-disability-specific settings – have adequate access to community-based health care services and care coordination services. In particular, California should examine its provider networks and rate structure to ensure that people with disabilities have access to doctors with expertise in working with adults with disabilities, outside of congregate residential settings. Particular emphasis should be given to investments in consulting and training infrastructure to enhance the ability of clinicians in the general population to serve people with I/DD, including those with complex needs; to expanding the scope of available clinical education and training opportunities to meet the needs of this community; and to investing in quality metrics to track outcomes for people with I/DD in both clinical and non-clinical contexts.

We would welcome the opportunity to communicate with you further on this matter. Please don't hesitate to refer questions to Samantha Crane, Director of Public Policy for the Autistic Self Advocacy Network, at scrane@autisticadvocacy.org or via telephone at (202) 509-0135.

Sincerely,

Samantha Crane
Director of Public Policy
The Autistic Self Advocacy Network