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June 9, 2016

Statewide Transition Plan Team 1570 Grant St. Denver, Colorado 80203 STP.PublicComment@state.co.us

RE: Comments to May 5, 2016 Statewide Transition Plan

Dear Sir/Madam:

Thank you for the opportunity to comment on Colorado's May 5, 2016 Statewide Transition Plan (STP) outlining Colorado's plan to ensure that Medicaid Home and Community Based Services are provided in settings, and pursuant to a person-centered planning process, that meet the Centers for Medicare and Medicaid Services' March 2014 rule.

Disability Law Colorado (DLC) is the designated Protection and Advocacy (P&A) System for Colorado under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 ("DD Act"), 42 U.S.C. 15001 *et seq.*, the Protection and Advocacy for Individuals with Mental illness Act ("PAIMI Act") 42 U.S.C. §10801 *et seq.*, and 29 U.S.C. § 794e, *et seq.*, the Protection and Advocacy of Individual Rights Program ("PAIR"). DLC has the authority to conduct investigations of allegations of abuse, neglect, and rights violations of people with disabilities, and to advocate for the rights of individuals with disabilities. Since its designation as Colorado's P&A System, DLC has represented more than 25,000 people with disabilities, provided information and technical assistance to more than 130,000 people, and reached more than 100,000 Coloradans through education programs and publications. As the P&A, DLC has worked with many individuals receiving services in a variety of Medicaid-funded settings, and assisted many individuals to assert their right to self-determination and live in a more integrated setting.

DLC provides the following comments regarding the STP.

INFRASTRUCTURE: STAKEHOLDER ENGAGEMENT AND OVERSIGHT

1. All STP documents should be available for public comment

Many documents cited in the STP, which are an integral part of the Department of Health Care Policy and Financing's (the Department's) transition plan, are not posted on the Department's website, or otherwise readily available for public review. DLC recommends that all documents referenced in the STP be made available for public review and comment. For example, the following documents are referenced in the STP but not available on the website:

• The Provider Transition Plan ("PTP") Excel file and PTP User Manual, referenced in Box 13 of the May 5, 2016 STP.

- The Protocol for Site Visits and Heightened Scrutiny, including the Checklist for site visitors, referenced in Box 13 of the May 5, 2016 STP.
- The draft template with minimum requirements for a residential agreement, referenced in Box 29 of the May 5, 2016 STP.
- The protocol and draft template for managing ongoing non-compliance issues with the HCBS Setting Rule, referenced in Box 48 of the November 16, 2015 STP.

It is difficult to provide meaningful comments to the STP without having access to these documents. Among other important aspects of the STP, these documents contain the self-assessment questions asked of providers and the instructions for the site visits. DLC obtained these documents through a public records request on May 20, 2016, leaving far less than 30 days for it to review the documents and complete its comments by June 9, 2016. The public should not have to make a public records request in order to review and comment on these important pieces of the STP.

Additionally, the Department should make sure that all information related to the STP that the Department has already posted on its website is available from one central location on the website. The Department has some information regarding the state's transition plan available at www.colorado.gov/hcpf/home-and-community-based-services-settings-final-rule, and some information at www.colorado.gov/hcpf/hcbs-waiver-transition. At the very least, there should be links from each website to the other so the public can easily access all of the information that the Department is making available regarding its STP.

2. Stakeholder meetings and committee meetings should be identified in the STP and contact information provided in the STP.

The STP refers throughout to several stakeholder meetings and advisory committee meetings. See Lines 4, 7, and 8 of May 2016 STP. For example, the Department states that it "is talking about adding a standing agenda item to the regular stakeholder meeting." See Box 8 in May 2016 STP. The Department states that it has held "stakeholder workgroups" for residential and non-residential settings to discuss concerns, best practices and other issues. Additionally, the STP refers to a stakeholder workgroup regarding supported employment, and that part of the group's mission was to create best practices. See STP Box 7 of May 2016 STP. Information about how to find out about the groups' members, the meetings, and the work produced by the workgroup or committee should be provided in the STP, including contact information for the Department staff person in charge of the meeting so the public is readily able to obtain information about the group and its word.

3. The Department should make correspondence from CMS public.

In the Summary of Changes to Home and Community Based Services (HCBS) Statewide Transition Plan (STP) from November 2015 to May 2016 found on the Department's website https://www.colorado.gov/pacific/hcpf/home-and-community-based-services-settings-final-rule, the Department reports that CMS provided comments to the November 15, 2016 STP.2 via a letter

dated January 12, 2016 and subsequent emails. CMS is also requiring the Department to submit quarterly updates. CMS's correspondence to the Department on the STP, particularly the January 12, 2016 letter, should be made available to the public and posted on the Department's website so the public can understand CMS's concerns, better understand the Department's STP, and provide more meaningful input to the STP.

INFRASTRUCTURE: SITE SPECIFIC ASSESSMENTS

1. The STP does not describe what will happen to the 145 providers who did not complete the self-assessment surveys or whose responses could not be linked to a provider.

The STP does not break down this number to specify how many providers failed to complete the self-assessment and how many surveys could not be linked to a provider. The STP should explain that, as well as explain how the problem of linking responses to providers will be remedied in the future. The latter is particularly important so that survey responses from participants, family members, and advocates can be linked to a specific provider.

In its Change Log dated November 16, 2015, the Department indicated that providers who did not complete surveys 1 and 2 would be reminded to complete the survey, and that those who did not complete the self-assessment would be considered non-compliant. Four months later, the March 2016 provider scorecards still shows that 145 providers did not respond to the survey.

It is not clear from the May 5, 2016 STP if the state is allowing these providers an additional opportunity to complete a self-assessment. If the state is allowing the providers who failed to respond to the first two surveys an additional opportunity to complete a survey through the provider transition plan (STP May 2016, Box 13 "the provider transition plan is an Excel document that the provider completes in order to assess its compliance with the HCBS Settings Rule, assess the potential application of heightened scrutiny, and set out a remedial action plan and timeline"), then the Department should include these providers in the site visits, and not rely on them being randomly selected for a site visit. The providers' failure to complete two surveys already sent to them indicates a reluctance or inability to take necessary steps to comply with the HCBS rule, and warrants a site visit for validation of the self-assessment. The Department should also be more active in overseeing these providers' development of a transition plan, having reviews more frequently that just every six months.

2. The STP does not explain how clients or other community stakeholders are involved in preparing for site visits.

The Department states in Box 13, which action item entails preparing for on-site surveys, that client and other community stakeholders are key stakeholders in conducting the work, but the STP does not explain how clients and other community stakeholders are involved. There is no indication in the plan that clients or 'other community stakeholders' were allowed to provide any input in developing the provider self-assessments or the participant, family, and advocate survey tool, or the provider transition plan, or PTP User Manual or Protocol for Site Visits and Checklist for site visits, all referred to in Box 13 of the May 5, 2016 STP. The STP should explain how these stakeholders will be involved in preparing for the site visits.

3. An independent party should distribute and collect individual and family surveys, and the identity of individuals and family members who respond to the survey should be kept confidential.

It appears that the Department is actively seeking input from participants of all providers, not just those providers who are randomly selected for site visits. *See* HCBS Provider Transition Plan User Manual, Appendix D. This is particularly important in light of the Department's decision to reduce the number of site visits it conducts.

However, the STP indicates that the Department is seeking individual and family member input by "asking all providers to work with the individuals receiving waiver services to complete the survey." *See* Box 12 of May 5, 2016 STP. The Colorado HCBS Final Rule Provider Validation Process explains that the providers will be required to distribute the individual and family survey to clients and is responsible for getting clients and clients' families to complete the survey. *See* p. 4. The Department should not have providers distribute and collect the survey, or encourage providers to be directly involved in assisting recipients in completing the survey, due to the conflict of interest. The provider has a financial interest in the outcome of the survey and also has control over many aspects of that participant's life. Asking providers to work with participants to complete the survey creates a potential for biased results.

The Department does not explain how the provider will collect the individual and family surveys while protecting the identity of the individual or family member from the provider. The Department will also require that the site visit team have a detailed review of the individual and family survey results with the provider. *See* Colorado HCBS Final Rule Provider Validation Process, at 5. This should only be done if it can be done without revealing the identity of the client or family member.

Failure to protect the identity of participants who respond to the survey lends itself to biased results, because participants may not feel comfortable providing candid responses if their identities are not protected.

The Department also described in its November 16, 2015 plan, Box 13, that it would 'push out' the survey to families and individuals on a quarterly basis. The STP does not explain what it means by "push out," and the plan to push out the survey is not included in the May 5 2016 survey.

The Department should explain its plan to obtain ongoing input from clients, family members and advocates after the March 2019 transition deadline.

4. The Department should develop a plan to provide ongoing education to participants and family members about the new rule.

The STP indicates that the Department is engaging in numerous efforts to educate providers about the HCBS regulations, an important piece of the transition plan, but not much effort specifically designed as outreach and education to participants. There does not seem to be a clear plan to educate participants about their rights to receive services in fully integrated settings so that they can provide meaningful feedback.

The information provided on the front of the individual and family survey does not provide a sufficient explanation of the HCBS rule and individual rights. For example, the chart lists characteristic of the home as "you can be active in the community" and "you have legal rights and protections." These vague terms need to be clarified through examples.

5. The Department should use the participant survey to validate the provider self-assessments given that the Department has reduced the number of site visits it will conduct.

The STP is contradictory about whether the state intends to use the participant surveys to validate provider self-assessments. *Compare* Change Sheet dated November 16, 2016, p. 2 ("Data from individual, Family and Stakeholder survey and from NCI will be used to track over all implementation through the state, but not to validate particular providers' responses") and May 5 2016 STP, Box 12, ("results [of individual and family surveys] will inform processes and providers and/or locations that need additional support" and "Many survey respondents have elected to identify the particular setting at which they or their family ember receive services, which allows their responses to be used in the site-specific assessment process"). Because the state is reducing the number of site visits it will conduct, the independent surveys completed by participants, family, and advocates become a more important tool to assess provider compliance with the HCBS regulations.

DLC is pleased to see that the Department is willing to consider adding site visits based on client or family responses or public input, even if a setting was not part of the 231 randomly selected settings selected for a site visit.

6. The provider survey in the provider transition manual asks questions some providers will not have information about and does not match the participant survey.

The provider survey in the provider transition manual asks questions that the provider is not necessarily going to know the answer to. For example, the provider transition manual asks "Do individuals have a choice of where they live?" *See* HCBS Provider Transition Plan User Manual, Appendix B, p. 19 and Appendix C, p. 31. A host home provider or group home provider is not going to have information about what choice an individual was given of where to live. The provider is not a good source of this information. Nor is the host home provider or group home provider going to know whether the individual visited other settings before making his or her choice. *Id*.

The provider survey in the HCBS Provider Transition Plan User Manual and the participant, family, and advocate survey do not ask the same questions. The participant survey does not ask about a lease agreement. The participant survey does not ask if restraints are used. The participant survey does not ask if the participant can lock his/her bedroom door. These questions are asked in the provider survey. Additionally, the term "personal choice" in the participant survey is not really explained with examples as it is in the provider survey. For example, the provider survey asks whether individuals can decorate their bedrooms as they choose and wear the cloths that they want. The participant survey does not have these questions. Because the surveys do not match, it makes it more difficult to validate the provider self-assessment.

7. The individual and family survey appears to have significant design flaws that could confuse respondents.

The Department's Survey for Individuals, Families, and Advocates section titled "Questions about the Workplace" has headings listed in grey that talk about the home, instead of the workplace. For example, one heading states "Choice: The regulations require that you have a choice of where you live. The following questions are designed to find out if you home is in line with the requirement." The questions below this heading asks "Do you feel you have the support to seek a volunteer opportunity, paid job, or participate in a day program in the community?" The mismatch between the heading "Questions about the Workplace" and the questions about the home could cause confusion for survey responders.

8. Additional comments

The STP does not leave enough time for the heightened scrutiny process to be completed. The Department proposes to wait until March 2018 to submit the list of providers who will undergo heightened scrutiny to CMS. This does not leave enough time to complete all the tasks necessary in order to ensure all individuals are in appropriate setting before March 2019. Specifically, that leaves only one year after the Department submits the list of providers for heightened scrutiny to CMS for review, the Department to determine whether individuals will be transitioned, the Department to assess capacity for the services to be provided by another provider, and transition to be completed.

The Department should assess current capacity of non-disability specific settings and develop a plan to increase capacity of those settings.

The STP does not explain at what point before the March 2019 it will place a moratorium on new placements in settings found to be noncompliant and not able to reach compliance.

Thank you for your consideration of DLC's comments.

Sincerely,

Claire Dickson

Attorney Coordinator

Protection and Advocacy for People with

Developmental Disabilities (PADD) Program

xc: Ondrea Richardson, Centers for Medicare and Medicaid Services