

FOR NCCDD ONLY
DRAFT COMMENTS: UNDER REVIEW BY SEG
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To: NC Department of Health & Human Services
From: NC Stakeholder Engagement Group
Re: HCBS Rule Transition Plan Feedback
Date: February 2, 2015

The North Carolina Stakeholder Engagement Group (NC SEG) is comprised entirely of individuals receiving services and supports from the MHDDSA system and family members. The Stakeholder Engagement Group goals are to: 1) increase participants' knowledge and understanding of managed long-term services and supports; 2) articulate the strengths and weaknesses of the current system to key decision makers; and 3) disseminate information to the constituent groups across the state.

At our January 16th meeting, NC SEG members discussed the HCBS Transition Plan at length and would like to submit the following comments for consideration to the Department of Health and Human Services (DHHS):

The NC SEG appreciates the following components of the plan/process:

- We appreciate the opportunity for the general public to provide public feedback, and also appreciate DHHS participating in our NC Stakeholder Engagement Group meeting to solicit feedback from us directly.
- We appreciate that transportation services will be evaluated as part of the Plan. Transportation is integral for most individuals to live inclusive and self-directed lives.
- We appreciate that the HCBS Taskforce Team contains family members and consumers.

The NC SEG believes the following steps should be taken to communicate about the HCBS Rule to the general public:

- DHHS needs to hold separate listening sessions for individuals and consumers in order to receive honest feedback. People are afraid to speak when there are providers in the room. There is a broad and deep fear of retribution from providers; it is pervasive among people with DD.
- DHHS should take a more efficient, systematic, cohesive approach to gathering stakeholder feedback. The recent series of listening sessions of various kinds would be more effective if the information from each were consolidated and shared among efforts.
- Listening sessions need to be held where/when consumers can get to the meeting.
- When asking for feedback, DHHS needs to structure information to be reviewed and feedback requests in a way that is not overwhelming to consumers and family members. Many consumers and families need a better understanding of how these rules apply to them.
- Listening sessions should be advertised widely. There is a large group of people who don't see themselves in this initiative yet. We need input from more than just those who receive the waiver and traditional respondents.

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The NC SEG has the following concerns with this rule/process:

- We are concerned that the HCBS Transition Plan Process is being rushed, reducing quality of feedback to meet the federally mandated deadline.
- We are concerned that the provider assessment process does not include feedback from consumers and family members. To truly determine how well providers are meeting the HCBS mandate, the self-assessment tool should incorporate feedback from consumers.
- We are concerned that there is not more specification in the Transition Plan regarding the quality control and oversight of the provider self-assessment to validate the accuracy of these self-assessments.
- We are concerned about the lack of clarification regarding DHHS's role in the Transition Plan.
- We are concerned that currently the self-assessments are "setting" based, not accounting for individuals' ability to be employed and make money. Having jobs and resources is essential to achieve community inclusion and involvement beyond settings.
- We are concerned that consumers and family members might not be able to meaningfully participate in the listening sessions, due to:
 - Lack of access to transportation to attend;
 - Lack of general public's current knowledge of the HCBS Rules and Transition Plan; and,
 - Concerns about listening sessions not feeling like "safe places" due to the audience also containing their providers. Discussions are more robust when done privately or in consumer groups, verbally. Many individuals have a fear of retribution and are scared to write things down or speak negatively about providers in front of the provider.

The NC SEG would like to see the following changes in the Transition Plan:

- The transition plan should include the support of individuals and family members to participate in state meetings to provide meaningful feedback on the transition plan implementation on an ongoing basis.
- DHHS needs to create an assessment for consumers that provides them the opportunity to assess their providers' compliance with HCBS Rules. Ideally the consumer assessment would align with the provider self-assessment to provide a different perspective on service provision. The value of the individual's voice is best seen in the comparison of his/her perception with that of the provider. The creation and utilization of a consumer self-assessment would create a "gap analysis." It would tell providers and the state where best to invest their time and energies in the years to come. The NC SEG stands ready to assist in the development, review or participation in a consumer assessment.
- More detail related to ongoing efforts to engage consumer and family member stakeholders throughout the duration of the 5-Year transition plan. The supports necessary for that participation should be specified in the transition plan.

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The NC SEG would like to see the following changes to the execution of the Transition Plan (Long Term):

- DHHS needs to provide supports for consumers and family members to participate in state meetings (CFAC, workgroups, etc.) to gain meaningful feedback on an ongoing basis. The Department should help people who want to participate to participate.

The NC SEG has the following questions they would like clarified:

- Is crisis intervention planning a part of this process?
- What is DHHS comparing the provider self-assessment feedback against to ensure quality?
- How does DHHS know if HCBS requirements have been met?
- Is the provider self-assessment going to be provided to the consumers of the providers?
- Is there a requirement that providers educate consumers about the self-assessment process?
- How can consumers be involved in the self-assessment process?
- How broad will the self-assessments go? How will the self-assessments address waiting lists?

The NC Stakeholder Engagement Group appreciates the opportunity to provide feedback on HCBS Final Rule Transition Plan. We stand ready and able to assist the Department of Health and Human Services by providing a consumer and family member perspective on this policy and others moving forward.

Respectfully,



Ronald D. (Ron) Reeve
Chairman, NCCDD

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