

March 20, 2015

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Acting Administrator  
Center for Medicaid & Medicare Services  
U.S. Department of Health and Human Services

Vicki Wachino  
Acting Director  
Center for Medicaid and CHIP Services  
U.S. Department of Health and Human Services

Dear Mr. Slavitt and Ms. Wachino:

We are writing to express our disagreement with the decision by the Centers for Medicaid and Medicare Services (CMS) to approve 1915(c) waiver funds for the residential housing and day services on the grounds of the North Dakota Life Skills and Transition Center (LSTC), a state funded intermediate care facility. We believe these settings and services do not meet CMS' new requirements for Home and Community Based Services (HCBS) settings. We believe that, had the heightened scrutiny review included the full range of stakeholder input intended in the rule, the outcome would have been different. We urge you to reverse your decision and use the lengthy waiver transition period states are provided to transition residents into appropriate community settings. Our issues with this decision pertain to two main areas, Insufficient Heightened Scrutiny Review and Insufficient Evidence by the State Demonstrating That LSTC Meets the HCBS Requirements.

Insufficient Heightened Scrutiny Review

There was a lack of public input during the review process. CMS rules state that the heightened scrutiny process is based, among other factors, on input from the public. There are further references to input from stakeholders, even going so far as mentioning specific consumer advocacy entities (e.g., protection and advocacy agencies). Given the repeated mention of the need for public input and the specific identification of consumer advocacy entities as relevant to the review process, we do not understand why our organizations were kept in the dark about the scheduled review and why the reviewers made no effort to seek the input of our organizations.

We clearly meet the stakeholder standard of entities with knowledge of whether the LSTC cottages have the qualities of HCBS. Indeed, the North Dakota Protection and Advocacy Project (P&A) maintains an office on the campus of LSTC and has an understanding of the daily life of cottage residents and administration of the residential and day programs. CMS was put on notice of this unique knowledge in the November 14, 2014 comments P&A submitted expressing concern that the state was seeking heightened scrutiny review of the LSTC residences.

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The process used by CMS site reviewers was not transparent. We were not informed that a review was scheduled and not contacted during the site review. It was not until we learned that the waiver had been approved that we discovered that a site review had taken place. We are left to wonder whether our concerns, raised in the protection and advocacy comments, about the state's application of the LSTC residences for heightened scrutiny, were weighed at all by CMS. In a meeting we had with ND Dept. of Human Services (DHS) administrators on March 18, 2015, we were told that DHS staff was told by the site reviewers to NOT tell others about the site review and to keep the information on a "need to know" basis. DHS said they even had to ask the site reviewers whether DHS could even discuss the pending review within their agency.

We have not been offered information about the site review. We do not know who conducted the interviews or their professions, and we do not know how many people were interviewed. This information would allow us to consider whether their responses may have been biased by financial or employment interest. We have had to submit a FOIA request in February 2015 to get the CMS' contractors report and are still awaiting the information.

#### Insufficient Evidence by the State Demonstrating That LSTC Meets the HCBS Requirements

The CMS rules require that North Dakota submit evidence to CMS sufficient to demonstrate that the setting does not have the characteristics of an institution and does meet the HCB setting requirements. Below, is information on the "exploratory questions on settings that isolate" provided by CMS. Applying our knowledge of LSTC and its residents and our expertise on community integration, the LSTC cottages do not meet the requirements of the rule.

The CMS rules require that settings are community based. However the LTSC setting is designed specifically for people with disabilities, and more specifically for people with intellectual and developmental disabilities. The residential cottages are on a campus called the Life Skills and Training Center. The name itself signals that it is different from a typical sub-division. It signals that the campus is designed specifically for people with disabilities. More important than the name, is the longstanding presence in the community of the LSTC as a State institution for segregation of its residents. The cottages for people with disabilities are located on the same grounds as an ICF, instead of scattered in neighborhoods off campus. This placement on a medical campus carries with it the message that people who live here have medical needs.

A cottage resident may in fact leave campus for hours each day, but the fact that they return to this medical sounding, segregated setting each night, automatically carries with it that stigma that the resident is some how less capable of full integration in the community.

The cottages are located on the grounds of the ICF and are operationally related. P&A maintains an office on the grounds of the LSTC and have seen many examples that show that the ICF and the cottages are operationally related. First, the two settings

share providers in order to make up for staff shortages at either location. Second, it is not uncommon for individuals at the day program to go to the ICF for lunch.

The State has not submitted evidence that the setting was selected by the individual. It is not clear from the information provided that the individuals in these settings were given a choice of available options, including a non-disability specific option, of where to live and receive services. The state transition plan says, "In addition to the on-site visits, *some* plans were reviewed and individual's choice of services was documented." (Emphasis added). In the response to comments about the institutional nature of these settings, the State responded, "Some of the individuals living on the grounds of the State ICF have been unable to successfully secure housing or services off the grounds of the State ICF..." and "Other individuals/guardians have made the choice to receive services in these settings." These responses do not indicate that the State has made community-based housing and necessary supports and services for their needs available to these individuals.

We believe that the inability to find alternate services may reflect more on the State's lack of community based housing options and services than on one's choice to stay in the current setting. The State says that the residents are "assessed at least annually to determine if alternate settings are available..." This statement does not offer assurances that alternate settings that are appropriate and desirable for the individuals have actually been offered or that the individual understands the choices offered. Our concern is heightened by the fact that the CMS reviewers would not have had the information to confirm whether appropriate services could be made available, because they do not appear to have talked to consumer advocacy agencies who maintain information about the full array of community options.

P&A's comments to the draft transition plan pointed out the inconsistency that the residents had freedoms and "maximum independence" yet some have not been able to find alternative settings. Additionally, the State's information says that one person enjoys this setting more, but the state left out any information as to what setting the person was referring to and any efforts that the State has made to educate the person about the choices currently available and what that experience would be like in comparison to his previous setting.

The CMS regulations state that settings must reflect individual needs. We have seen no evidence that these settings reflect the individuals' needs. The needs of individuals are not supposed to be measured by what is available to them, but by the needs and goals identified in a proper person-centered planning process.

As pointed out in P&A's comments on the draft HCBS transition plan, many if not all of these individuals are former LSTC residents and "it is important to consider the frame of reference shared by these individuals." There is no evidence that the individuals were educated about the opportunities they should have (e.g. in the same manner as individuals not receiving Medicaid HCBS services).

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One requirement of the CMS reviews is that the residents are in control over their own schedules or finances. Given the current circumstances and availability of information, there is no evidence that this requirement was met.

Individuals under this HCBS waiver must make informed choices about services and supports. There is no information about the individuals making an informed choice about from whom they receive services and supports. We have no evidence to suggest that individuals under this process were clearly able to make these informed choices.

We understand that this heightened scrutiny review process was invoked under the typical review of all of ND's HCBS waivers. We understand this is one of the first decisions using the heightened scrutiny process under the newest HCBS regulations. We are concerned that the decision reached in this process in North Dakota is not in line with the intent or specific requirements of the HCBS regulations and processes. Further, we are concerned that this decision could lead to an unfortunate set of unintended consequences not only for ND residents with developmental disabilities, but for others similarly situated across the U.S. Once again, we respectfully request that CMS review the processes, procedures, and decision in this case, and further we ask that the initial decision be reversed.

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