



June 25, 2014

Cynthia Mann
CMS Deputy Administrator/Director
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Ms. Mann,

On behalf of the three national associations of Developmental Disabilities Act programs, we write to express our appreciation for the new home and community-based services (HCBS) rule and to share some concerns of our members on the implementation of this new rule.

AUCD, NDRN, and NACDD represent the entities authorized in the Developmental Disabilities Assistance and Bill of Rights Act (PL 106-402) – University Centers for Excellence in Developmental Disabilities, Protection and Advocacy Systems, and State Councils on Developmental Disabilities – located in each state and territory. Together, our members improve the lives of people with disabilities through clinical practice, research, education, systems change, legal advocacy, and education of policymakers. Our members are encouraged with the work that CMS has done to establish the new HCBS rule. We view it as a monumental and positive change to community-living policy and hope to witness a profound improvement in the HCBS program and lives of people with disabilities. However, this cannot be realized if the rule is not implemented thoroughly and correctly.

Below are four key issues we would like to raise in this crucial first year of implementation. As our members are watching and participating in this process, a number of issues have been brought to our attention that we feel compelled to share with you so that they may be immediately addressed and not hinder the effective implementation of the rule.

1) CMS Must Send A Strong Message To States on the Importance of Stakeholder Engagement

We are concerned about the lack of detail in the plans states have been releasing for public comment. In some states, the best and possibly only area of public participation on implementation of the new rule is through public comment. However, our members are seeing documents that are vague, short, and lack sufficient information on which to provide comment. These include plans that provide few details, plans on the assessment of settings with no indication that there will be public comment on the full transition plan, and single page documents that claim the state is already in compliance. These postings are simply insufficient.

While we appreciate that states are on tight timelines, these documents and comment periods should not fulfill requirements for public comment. If a state solicits comment on a short or vague plan, CMS should expect the state to provide further opportunities for public comment as

the state develops a more robust plan as well as opportunity for public comment on the final plan. Multiple opportunities for public engagement while a state develops a plan are preferable to single comment periods on scant or rushed plans.

Finally, we urge CMS to make clear that public comment must be invited on final and robust transition plans that meet certain minimal standards. These might include: timeframes for review of all HCBS settings, the process and mechanism used to review these settings, and standards for licensing, regulation, and reimbursement consistent with the new rule.

2) States Need More Guidance

CMS has not provided enough guidance on implementation of the rule. The vague and short documents described above are often posted as states await further guidance. We strongly encourage CMS to provide states with all necessary guidance, especially the guidance on application of the rule to non-residential settings and on requirements for public engagement on a robust transition plan, as soon as possible. Such guidance should be in writing and posted publically.

3) Federal Agencies Must Speak with One Voice

Our members have experienced inconsistency in messages from CMS, including inconsistencies between National and Regional CMS offices and messages that appear to vary by audience. They are concerned that there has not been enough training of the regional CMS offices to have messages that are consistent with the federal office. Different states appear to have different impressions of expectations for transition plans. For example, advocates report hearing that timeframes are flexible and that plans need only address process not the details of how the state will operate its HCBS programs in accordance with the new regulations. These impressions are exacerbated by the dearth of written guidance provided by CMS. Ensuring that the same message is relayed to all levels of contact, regionally and federally, is of utmost importance. We hope that by bringing this to your attention, we can eliminate any inconsistencies and make sure that everyone is hearing about the importance of implementing the new rule as a high priority. CMS should also work closely with the Department of Justice and the Administration for Community Living to ensure full consistency of messaging and interpretation across federal agencies.

4) CMS Must Ensure Transparency

Our members represent three key stakeholders in state disability communities. However, it is clear that many of our members are not kept informed of how their states are moving forward in implementing the rule. CMS should encourage, if not require, states to post transition plans and public comment periods on the homepages of the state's Medicaid agency websites.

We also request that CMS provide more information on the review of transition plans, including posting transition plans (within one week of submission) on Medicaid.gov and sharing information on the review process (including criteria or performance measures). This necessary

transparency will help our members engage in the stakeholder input that is crucial to proper implementation of the rule, both when states are developing plans and when CMS reviews those plans.

Our members represent family members, people with developmental disabilities, and legal and research experts in the field of disability. We seek to uphold and bring attention to the new HCBS rule as much as possible; it is the most impactful change in the provision of community-based services in years. Without proper implementation, this rule is at risk of losing its power to live up to its purpose. We want to work with you to preserve this wonderful policy change and to preserve the impressive legacy of this Administration to take on this challenging work. Please let us know how we can assist and thank you for allowing us to share some of our concerns as we move towards a shared goal of ensuring that Americans with disabilities can live in the most integrated settings and participate in all aspects of community life.

Sincerely,



Donna Meltzer
CEO, NACDD



Andrew Imparato
Executive Director
AUCD



Curt Decker
Executive Director
NDRN

Cc:

Ralph Lollar
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