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April 27, 2012

Cynthia Mann

Deputy Administrator and Director

Center for Medicaid, CHIP, and Survey & Certification

Centers for Medicare & Medicaid Services (CMS)

7500 Security Boulevard, Mail Stop S2-26-12

Baltimore, Maryland 21244-1850

Re: Proposed 1915(i) Option in North Carolina

Dear Ms. Mann:

We, a broad array of stakeholders, write to express grave concerns about certain aspects of North Carolina's application for a Section 1915(i) option. Our stakeholder group includes state and national mental health consumer and family groups, service providers, and a former state mental health director.

North Carolina has a history of adopting policies that reflect an institutional bias. We urge you to scrutinize the state's 1915(i) proposal carefully and ensure that whatever CMS ultimately approves does not perpetuate this bias. Most people with disabilities prefer to live in their own homes rather than large congregate settings. North Carolina's 1915(i) proposal, as currently written, would ignore that preference and continue the needless institutionalization of the thousands of individuals with mental illness and intellectual and other developmental disabilities in adult care homes in North Carolina.

Adult Care Homes are Institutions and Should Not be Considered Home and Community-Based Settings

The 1915(i) option could be a useful tool to enable North Carolina to offer residents of large, substandard adult care homes the opportunity to be served instead in their own homes. Indeed, other states have used this option to promote innovative and flexible services in integrated settings, in contrast to North Carolina's proposal to use the option in a way that relies on old service delivery models and does little to promote integration. As you indicated in your May 20, 2010 letter to state Medicaid directors, the 1915(i) option "offers great promise as a tool to prevent institutionalization" and provides "State plan opportunities to serve individuals in the most integrated setting."

North Carolina's proposed 1915(i) option, however, turns this purpose on its head by including large adult care homes among the "home and community-based" settings covered under the option. Adult care homes are neither home- nor community-based, nor are they the most integrated setting appropriate for individuals with mental illness or intellectual or other developmental disabilities.

Last year, the U.S. Justice Department conducted an investigation of North Carolina's adult care homes and concluded that the state was violating the Americans with Disabilities Act (ADA) and the *Olmstead* decision by failing to ensure that the thousands of individuals with mental illness living in adult care homes are afforded the opportunity to live in more integrated settings such as supportive housing. The Department concluded that "[a]dult care homes are institutional settings that segregate residents from the community and impede residents' interactions with people who do not have disabilities."¹

The Justice Department's findings noted that these homes "appear and function as institutions, not homes where people without disabilities live. People with mental illness who reside in adult care homes live in close quarters primarily with other persons with disabilities, and most aspects of their daily lives are highly regimented and limited by rigid rules and practices."² Residents of many homes are monitored on video screens, many facilities have curfews as well as highly regimented meal and medication times, and some facilities forbid residents from leaving the grounds unaccompanied or restrict where they may go. Community outings are limited and rigidly scheduled, with residents typically travelling together as a group.³

The "community living standards" proposed in North Carolina's 1915(i) application would not convert North Carolina's large, institutional adult care homes into home and community-based settings. Affording residents telephone access, visitor access, kitchen access, the "ability to work with the facility to achieve the closest optimal roommate situations," the ability to participate in community activities, the assurance of "maximum possible privacy" in the delivery of personal care services, and other similar measures would not change the fact that these are segregated institutional settings where residents live highly regimented lives.

Approving the current version of the 1915(i) option would not only be inconsistent with the Justice Department's findings and incentivize continued institutionalization; it would also set a troubling precedent for other states around the country.

The 1915(i) Option Should Not Be Limited to Individuals Who Require On-site Services

A second concern we have with North Carolina's proposed 1915(i) option is that it appears to be limited to individuals who require "24 caregiver availability."⁴ It is unclear what this requirement means,

¹ Letter of July 28, 2011 from Thomas E. Perez, Assistant Attorney General, U.S. Department of Justice, Civil Rights Division, to Hon. Roy Cooper, Attorney General of North Carolina, at 1, http://www.ada.gov/olmstead/documents/nc_findings_letter.pdf.

² *Id.*

³ *Id.*

⁴ North Carolina §1915(i) HCBS State plan Services Application, at 12.

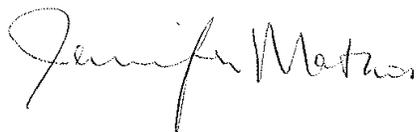
and we presume that CMS will require clarity before approving any 1915(i) option.

If the 24-hour caregiver availability requirement means that the 1915(i) option will be available only to individuals who have services located on-site in the same building where they live, the option will exclude most individuals living in supportive housing, including individuals who move from adult care homes to supportive housing. If the 1915(i) option were permitted to cover individuals in adult care homes based on the availability of services on-site, but would not cover these same individuals if they moved to scattered-site supportive housing, it would perpetuate their needless institutionalization. This would create a new *Olmstead* problem and would undermine the Justice Department's efforts to resolve the current *Olmstead* violations concerning adult care home residents. It would also subvert the recent ruling by a federal judge that North Carolina is violating *Olmstead* as well as the Medicaid Act's comparability requirement by imposing higher standards for receiving personal care services in community settings than in adult care homes. *See Pashby v. Cansler*, 2011 WL 6130819 (E.D. N.C. Dec. 8, 2011) (issuing preliminary injunction).

We hope that CMS will take these concerns seriously and will approve a 1915(i) option only if it excludes adult care homes and does not require that participants need 24-hour on-site service availability. A 1915(i) option that is structured to perpetuate institutionalization in adult care homes rather than to promote a much-needed expansion of the integrated settings in North Carolina's existing community system would be inconsistent with *Olmstead* as well as the Medicaid Act.

Thank you for your consideration.

Sincerely,

A handwritten signature in cursive script that reads "Jennifer Mathis".

Ira Burnim
Jennifer Mathis
Bazelon Center for Mental Health Law
Counsel for North Carolina Stakeholders Listed Below

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cc: Barbara Edwards