



Nothing about us without us!

October 7, 2014

Honorable Marilyn Tavenner
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, Maryland 21244

Dear Administrator Tavenner:

We recognize that you received a letter from Wisconsin Department of Health Services Secretary Kitty Rhoades on August 21 taking the position that it should be able to use HCBS funding for segregated pre-vocational and day services settings. As a national disability rights organization representing the interests of people with intellectual and developmental disabilities, we strongly disagree. The new HCBS settings rule clearly prohibits use of HCBS funding in settings, such as sheltered workshops, that fail to provide individuals with disabilities with full opportunities for competitive, integrated employment.

The Autistic Self Advocacy Network supports the positions articulated by the Wisconsin Board for People with Developmental Disabilities (BPDD) and Disability Rights Wisconsin (DRW), the state protection and advocacy agency, both of which requested specific guidance from CMS on community-based pre-vocational services for participants in HCBS waiver programs.¹ This guidance should clarify that vocational services, adult day habilitation, and similar services must meet the standards established in the new rule, including maximizing opportunities for HCBS waiver recipients to fully enjoy community living and receive services in the most integrated settings. Given the disproportionately high percentage of individuals receiving funds through the Family Care and IRIS (self-directed services) waivers who are working for subminimum wage in sheltered workshops, we believe that without strong guidance from CMS, people with disabilities will continue to be shunted into segregated and restrictive settings without any meaningful opportunities for participation in the community or integrated employment.

The Department of Justice has taken the position that state practices that divert individuals with disabilities into sheltered workshop and segregated day settings constitute unlawful disability-based segregation.² Nevertheless, Wisconsin currently has the fourth highest rate of people per capita receiving services in sheltered workshops funded through HCBS waivers. Despite multiple efforts to shift currently available resources toward services, such as supported employment, that increase opportunities for integrated employment, Medicaid HCBS funding for Wisconsin continues to be used extensively for long-term service delivery in segregated settings

¹ See Letter from Daniel Idzikowski to Marilyn Tavenner (Aug. 28, 2014); Letter from Beth Swedeen to Marilyn Tavenner (September 3, 2014).

² See Department of Justice, Letter of Findings Regarding its Title II ADA Investigation of Employment, Vocational, and Day Services for Persons with Intellectual and Developmental Disabilities in Rhode Island (January 6, 2014), available at http://www.ada.gov/olmstead/documents/ri_lof.pdf.

with little progress toward greater integration. The number of individuals in Wisconsin placed into sheltered workshops has been steadily growing, with over 1,000 additional people with disabilities receiving such placements in the past five years.

With the promulgation of the new HCBS regulations in the final rule published earlier this year, CMS has an excellent opportunity to fulfill the promise of community inclusion for people with disabilities. The final rule requires that all HCBS-funded services must be delivered in settings that meet the newly defined criteria for community-based settings. As Wisconsin's Department of Health Services begins to formulate its transition plan, it is critical to send a strong message that settings that do not presently meet the rule's integration requirements can – and must – change their models and practices to come into compliance with the regulations.

Contrary to the Wisconsin Department of Health Services' belief, the Final Rule does not merely require states to ensure that “at least some settings . . . give participants the same degree of access to the community as other individuals.” (8/21/2014 Ltr. from Kitty Rhoades to Marilyn Tavenner at 2.) The regulations require that *all* settings where HCBS waivers are used must be integrated into the community:

“Home and community-based settings must have *all* of the following qualities . . . : (i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings . . . *to the same degree of access* as individuals not receiving Medicaid HCBS.”

42 C.F.R. § 441.301(c)(4) (emphasis added).

Segregated, disability-specific settings fail to meet this requirement and therefore cannot be funded through Medicaid HCBS programs. Although the regulations also require that individuals be offered the opportunity to exercise choice among different integrated settings, the State must nevertheless “ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community.” 42 C.F.R.

§ 441.301(c)(2)(i). Although the state may choose to retain a “full compendium” of services in “all settings, both disability-specific and integrated into the community” (Rhoades Ltr. at 1), it may not use HCBS funds for placements in segregated settings.

There is a clear danger in failing to enforce the Final Rule's requirement that all covered settings be integrated into the community. In the absence of strong guidance, individuals with disabilities ultimately have fewer choices because service providers will assume that community-based options are not appropriate or sufficient for those with significant support needs. We agree with the analysis of DRW and Wisconsin BPDD that the likely result of granting the Wisconsin's Department of Health Services' request to use HCBS funds for segregated settings would be maintenance a status quo where people with disabilities are ostensibly offered a choice of service settings but are in reality constrained by an array of choices that only include segregated settings such as sheltered workshops, and are thus inappropriately and unnecessarily placed into these settings. Unless Wisconsin is required to transition away from this model, thousands of people

with disabilities in Wisconsin currently will continue to be isolated from their communities and prevented from making truly informed choices about their services.

Thus, we urge CMS to make it clear that such an approach would directly contradict the purpose and requirements of the Final Rule, which requires that all settings where HCBS funding is used must meet the new standards.

Thank you for your consideration of our concerns. Please don't hesitate to contact us with any questions related to this letter. We are confident that CMS is fully committed to implementing both the spirit and intent of the Final Rule, thereby ensuring that HCBS programs truly offer integrated, community-based alternatives to institutional settings.

Sincerely,

A handwritten signature in black ink, appearing to read 'Samantha Crane', written in a cursive style.

Samantha Crane
Director of Public Policy
Autistic Self Advocacy Network