



Nothing about us without us!

Justin Senior
Deputy Secretary for Medicaid
2727 Mahan Drive
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Tallahassee, FL 32308
Phone: (850) 412-4000

22 February 2016

Dear Mr. Senior,

We are writing regarding a service delivery setting in Florida that we believe is not in compliance with the recently-issued regulations on Home and Community-Based Services. We have identified The Villages at Noah's Landing (56 acres and initially 17 residential buildings in Polk County, Lakeland, FL and created by Noah's Ark of Central Florida) as an example of an impermissible setting that we would like to bring to your attention.

The final rule requires settings to be integrated in and support access to the broader community, provide opportunities to seek competitive integrated employment, support engagement in community life, and support control over personal resources. The final rule also requires that people with disabilities choose their own service settings and have choices that are not disability-specific. Additionally, CMS issued guidance that describes characteristics of settings that tend to isolate. One of those characteristics is a location where people with disabilities receive "residential, behavioral health, day services, social and recreational activities, and long term services and supports" all on the same site without having to leave.¹

The Villages at Noah's Landing is an example of a model that claims to be an alternative to large institutions or group homes but that in reality isn't community-based. These settings tend to isolate people with disabilities and prevent meaningful access to the broader community. People living in these settings are housed primarily with other people with disabilities. Although in some of these settings people without disabilities are invited to live in the same housing arrangements as service recipients with disabilities, these individuals are often staff members or volunteers. As a result, residents with disabilities often only interact with people in the surrounding community on specific dates or while working in provider-owned enterprises, such as a farm stand, or "community service" days in which members of the public are invited into the setting. This limits opportunities for full integration and sends a message that the residents with disabilities are projects, not peers.

¹ Centers for Medicare & Medicaid Services, Guidance on Settings That Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community 2, available at <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/settings-that-isolate.pdf>.

Disability-specific “farms” or “ranches” are one example of a setting that isolates people with disabilities. Residents with disabilities live and receive services entirely on the farm or ranch, which is usually owned by service providers. People with disabilities receive both housing and day services at the same site. Day services may include organized activities such as growing crops, raising animals, and other outdoors activities or crafts. Farm work may be unpaid or paid at rates below minimum wage. Disability-specific farms or ranches typically market these day activities as therapeutic or rehabilitative. Staff usually live on the farm or ranch. These settings are distinguishable from ordinary farms where people with disabilities may choose to live or work.

Villages and gated communities, like The Villages at Noah’s Landing, house many people with disabilities in a small cluster of homes in an area offset from the surrounding community. The entire village or gated community is often referred to as a “campus.” Staff usually live in the same buildings as residents with disabilities. A limited number of non-disabled people who are not staff may also live on the premises. Nevertheless, the properties are marketed as a special location only or mostly for people with disabilities and offer limited opportunities to interact with the community outside the confines of the campus. Residents with disabilities may have jobs inside the village or gated community, such as in a convenience store or in a sheltered workshop.

In addition to the geographic isolation of these communities, many settings also impose non-individualized restrictions on residents’ daily choices and activities, such as 24/7 surveillance cameras or motion sensors for all residents. The Villages at Noah’s Landing itself claims to have been developed with security cameras all over the campus and the residents are apparently under constant surveillance by state social workers and staff. Such violations of resident privacy by a provider-owned residential setting are in violation of the new home and community-based settings rule.

These settings must be contrasted with individual decisions to live with roommates or housemates who might also happen to have disabilities or to live on a farm, a ranch, or near the homes of other friends or acquaintances who have disabilities. These campuses are large settings that are intended to be largely self-contained, with residents receiving employment and day services in the same isolated setting.

The Villages at Noah’s Landing is not the only setting of its kind, as this particularly pernicious model of service provision has become increasingly popular nationally. As you move forward with the five-year transition planning process, we strongly encourage you to include strategies to transition people currently in these settings to other settings that are in compliance with the regulations.

We welcome further opportunity for discussion. Please direct any inquiries to our public policy director, Samantha Crane, at scrane@autisticadvocacy.org or (202) 509-0135.

Sincerely,

Handwritten signature of Ari Ne'eman in black ink on a light blue background.

Ari Ne'eman
President

Handwritten signature of Samantha Crane in black ink.

Samantha Crane
Director of Public Policy