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October 2, 2015

Comments Regarding Betty's Village Proposal

The Autistic Self Advocacy Network opposes the request of Betty's Village to receive HCBS (Home and Community-Based Services) funding from Nevada's Division of Health Care Financing and Policy (DHCFP). The Autistic Self Advocacy Network is a national non-profit advocacy organization run by and for Autistic people. ASAN was created to serve as a national grassroots disability rights organization for the Autistic community. It advocates for systems change and ensures that the voices of Autistic people are heard in policy debates, while working to educate communities and improve public perceptions of autism.

By its own description, Betty's Village does not meet the community integration standards the Centers for Medicare and Medicaid and Services (CMS) mandated in its January 2014 Final Rule on HCBS settings. Under the new rule, residential HCBS settings must be integrated into the community and must include meaningful safeguards for residents' autonomy, privacy, and access to the community. The final CMS regulations support the historic 1999 Supreme Court decision *Olmstead v. L.C.*, which held that the States must provide people with disabilities with "community-based treatment" and appropriate supports, 527 U.S. 581, 607 (1999). Over the course of the past two years, states have begun to submit Transition Plans to CMS which are designed bring state settings into compliance with the final CMS rule and the Supreme Court's decision in *Olmstead*.

In recognition of the particular risks associated with provider-owned residential settings, the Final Rule includes additional requirements for such settings. Residents in provider-owned settings must, among other things, have lockable doors, access to food or visitors at any time, and be physically accessible. 42 C.F.R. §§ 441.301(c)(4)(vi), 441.530(a)(1)(vi), 441.710(a)(1)(vi)).

In addition, the Final Rule bars HCBS funding from going toward settings that isolate people with disabilities - such as those on the grounds of a hospital or those that cluster people with disabilities together in a remote area - even if those settings might theoretically meet the additional requirements for provider-owned settings. A setting that isolates people with disabilities must be individually approved by CMS through a "heightened scrutiny" process and will not be approved to receive Medicaid HCBS funding unless it overcomes the presumption that it has the characteristics of an institution.

According to CMS' guidance on the final HCBS regulations, settings that: (1) are inhabited exclusively by people with disabilities, especially when they are only people with a specific disability; (2) provide multiple types of services on-site, including housing, behavioral,



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therapeutic, and recreational services; and (3) limit the residents' interactions with the community are presumed similar to institutions and must be approved under the "heightened scrutiny" process. Betty's Village, which would provide services to one hundred people with specifically intellectual disabilities, with all residences and services clustered onto a single campus, meets all three characteristics of institutions listed in CMS' guidance on § 441.301(5)(v) (Settings That Are Not Home and Community-Based, heightened scrutiny process) and therefore must undergo heightened scrutiny review.

We believe that Betty's Village does not meet either the standard for either provider-owned HCBS settings or the requirements of the HCBS heightened scrutiny approval process that it must undergo. In addition, the proposal by Nevada's Division of Health Care Financing and Policy (DHCFP) to finance additional segregated settings instead of financing the development of new, integrated residential settings violates the integration mandate in *Olmstead*. Settings like Betty's Village segregate people with disabilities from their communities and greatly limit their autonomy.

Specifically, ASAN finds that the following characteristics of Betty's Village are characteristics of an institutional setting and that the proposal is therefore ineligible for HCBS funding:

- 1. The design of the "Enlightened Living" program in Betty's Village does not allow the individuals living there the "individual initiative, autonomy, and independence in making life choices" or the "privacy" required in order for a placement to receive HCBS funding. 42 C.F.R. § 441.710(a)(1)(iv), (a) (1) (iii).**

The first two levels of the "Enlightened Living" program require 24-hour supervision by Betty's Village staff, which would necessarily involve a staff member who lives in the same residence as the person with a disability. This violates § 441.710(a)(1)(vi)(B) of the final regulations, which requires provider-owned settings to not limit the resident's choice in roommates.

The second level of support specifically describes a live-in "Resident Advocate." The proposal's language implies that the Resident Advocate would be involved in all major independent living decisions made by the person with an intellectual disability. Specifically, the proposal states that the Resident Advocate would be a "friend, sidekick, and developer" and would increase the individual's "personal, home, community and work skills" if the person wishes to "progress to the next level" of independent living. Despite this, there is no indication that the person with a disability has a choice about who the Resident Advocate is. The third, least restrictive level would still involve "intermediate supervision" by staff



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members in an apartment that would be on the Betty's Village complex rather than within the neighboring community.

This amount of involvement of the service provider in the personal life of the person with a disability greatly limits the amount of personal choice and autonomy in the setting. The Final Rule requires that such limitations on autonomy be narrowly tailored to an individual needs as specified in the Person-Centered Plan (PCP), and not applied across the board to all individuals in a setting. Specifying the "levels" of support Betty's Village provides, and tying them to an individual's location, would make compliance with this requirement impossible. Residents would not be able to customize the level of support they wish to receive.

Furthermore, the design layout included within this proposal shows that the Houseparents' Apartment where staff members reside can access any of the apartments belonging to residents from the common room. We feel that this design does not provide residents with sufficient privacy, which providers are required to provide in order to be eligible for HCBS funding. "Houseparents" have keys to all apartments and it is unclear whether or not it is possible for a resident to lock the door to their apartment. 42 C.F.R. § 441.710 (a) (1) (iii).

The proposal even states outright that private time will not be readily and immediately accessible to most residents. It states instead that the highest level of support involves 24/7 access intermediate level of support allows for some "approved alone time." This also violates 42 C.F.R. § 441.710(a)(1) (vi)(C), which requires that HCBS settings give individuals "the freedom and support to control their own schedules and activities."

2. The independent living, medical services, and financial services provided to the person with a disability limit their autonomy and "independence in making life choices" required by CMS' final regulations. 42 C.F.R. § 441.710 (a) (1) (iv).

Many of the support services provided to the person with a disability do not appear to sufficiently involve the person with a disability in the decision-making process. Meals are prepared by Betty's Village staff in the communal areas, which may limit the ability of the person with a disability to "control their own schedules" and "have access to food at any time." 42 C.F.R. § 441.710 (c)(4)(vi)(C). Medical support services such as nursing services are again provided by Betty's Village support staff, and the medical staff consults "family members and guardians" but not the person with a disability on the person's medical needs. Betty's Village PCP team notably is allowed to manage the financial resources of residents, which may limit the resident's ability to "control personal resources" as required in HCBS settings. 42 C.F.R. § 441.710 (a) (1) (i).



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3. The form of delivery of the social activities provided by Betty's Village discourages "individual initiative" and "independence." 42 C.F.R. § 441.710 (a) (1) (iv). The activities also do not involve community integration.

We feel that the form of delivery of some of the social activities provided by the center discourages personal autonomy and independence. According to the proposal, the Activity/Volunteer coordinator at the Village schedules a series of events that the residents can participate in each month. These activities include shopping, concerts, dining out, and volunteer projects to name a few contemplated. Outside interaction with local businesses during these events is described as being a teaching opportunity where people with intellectual disabilities "will have opportunities to spend their money" and "learn money management skills." These descriptions suggest both that the person will not normally have opportunities to spend money during the day (Violating again C.F.R. 441.710 (a) (1) (i)) and that support staff supervise the person with a disability constantly during these events. Based on this description, these events do not involve or encourage the independent, self-driven engagement with the broader community required in HCBS.

4. Betty's Village does not provide its residents with facilitation of "individual choice" regarding who provides "services and supports" in HCBS settings. 42 C.F.R. 441.710 (a) (1) (v).

Most of the services in Betty's Village (including nursing, financial, and independent living support services such as meal preparation and apartment tidying, and day planning) are provided by Betty's Village staff members. This does not allow the person a sufficient amount of choice in who provides these services to them, as mandated by the regulations. While the CMS regulations do not prevent residential service providers from requiring their residents to use their residential services, they do not allow providers to deny their residents individual choice of daily living and medical services.

5. The various proposals for community engagement listed in Betty's Village do not provide the full community integration, access to community support services, and "full access" to the greater community "to the same degree...as individuals not receiving Medicaid HCBS" as required by the final regulations. 42 C.F.R. 441.710 (a) (1) (i).

The setting proposes: (1) scheduled outings into the community, strictly under the supervision of Betty's Village staff, as noted earlier in this comment; (2) scheduled meetings between Betty's Village residents and various community organizations such as the Boy Scouts and athletic teams; (3) invitations to members of the public to come if they want; and (4) Betty's Village residents to schedule "unplanned spontaneous outings of their choice," a



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statement which is inconsistent with the highly regimented lifestyle and 24/7 supervision that would be provided by the facility. None of these pre-scheduled, group-based outings and activities would provide a resident with the full access to and engagement with the greater community of people without disabilities contemplated by CMS. Furthermore, inviting community organizations and residents such as the Boy Scouts into Betty's Village does not integrate the residents into the *community* at all. This "reverse integration" strategy merely gives community organizations visitation rights. It is also unclear from the proposal whether residents could "receive visitors at any time" as required by the provisions for provider-owned settings. 42 C.F.R. 441.710 (a) (1) (vi) (D).

6. The proposal does not indicate whether residents would be under a "legally enforceable agreement" that provides similar "responsibilities and protections from eviction" provided under Nevada landlord-tenant law, as required by CMS final regulations. 42 C.F.R. 441.710 (a) (1) (vi) (A).

ASAN strongly encourages CMS to reject the State of Nevada's proposal to fund programs such as Betty's Village using HCBS program funding, as programs of this kind are not truly home and community-based nor do they provide the residents with equal access to their communities. They instead reflect the characteristics of institutions and do not further the goals of either HCBS programs or the *Olmstead* integration mandate. For further information if necessary, e-mail Samantha Crane at scrane@autisticadvocacy.org.