

June 8, 2011

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2296-P
P.O. Box 8016
Baltimore, Md. 21244-1850

Submitted electronically: <http://www.regulations.gov>

Dear Centers for Medicare and Medicaid Services,

CMS-2296-P cites the Olmstead decision, in which “the Court affirmed a State's obligations to serve individuals in the most integrated setting appropriate to their needs.” Section 2 "HCBS Settings" of CMS-2296-P does not adequately address the wide spectrum of needs amongst people with intellectual disabilities. Since people who do not have disabilities are free to choose living in “intentional communities” based on needs or interests, why should people with intellectual disabilities be barred from making this choice for fear of losing their HCBS funding? A community should be selected by the individual that is appropriate to their own desires and needs – and not by Federal or State agencies on their behalf. The degree of integration should be balanced with other needs that person may have, but the choice should be left to the individual as to how much or how little integration is important to them. It is alarming to think that the Secretary would have the ultimate power to determine which setting is or is not a community. Government appointees should not have the final decision-making power in these matters – it should be up to the individual and their families.

CMS-2296-P Section 2 indiscriminately uses the word "segregation" in regard to community-based settings that serve individuals with intellectual disabilities. My brother has Autism and Down Syndrome and cannot verbalize his choices beyond his most basic needs. In the typical "integrated" setting, where he lived most of his life with his family in a typical residential neighborhood, he had no real choice for socialization with his peers. As an adult, he had an opportunity to live in a planned residential community in a small campus-based setting, and only then did he begin to make real friendships with people with similar interests and abilities. In this setting, my brother has a safe and secure environment to explore the first true freedom that he has ever known. He can walk to friends' houses, watch TV or play video games, eat meals when and with whom he chooses, and come and go to activities at his discretion. His communication has improved and he has become more independent than ever before.

The essence of the word "community" – which is a basic human need – is the ability and opportunity to spend time with people who have shared interests and abilities and who enjoy each other's company. In my brother's previous conventional "integrated" community, my brother was politely tolerated, but no one from the neighborhood actively sought his company or tried to include him in any real sense. In a campus-based setting such as the one my brother now lives in, he is able to grow as a person without the

constant supervision of parents and relatives. There are resident advisors to facilitate logistics, personal care, safety, and health, but this only augments my brother's freedom of choice, rather than limits it.

If my brother were to live in a group home or in Independent Supported Living arrangement, effectively he would have no freedom or opportunity to interact with the larger community.

A true community offers a sense of "belonging." If this sense of "belonging" is achieved by voluntary grouping of people based on similar needs and interests, it is unfair to call it "segregation."

In any larger community, smaller sub-communities can develop that are based on commonalities such as 55+ age or other voluntary reasons for grouping in a proximity. Individuals with special needs should have the freedom to live in a planned community whether or not other residents share a diagnosis. In a "money follows the person" model, the choice of location and person's own view of the community setting that best fits the "most integrated setting appropriate to their needs" should be respected and not disqualify the individual from HCBS funding.

In well-designed planned residential communities, such as the one my brother lives in, a very high percentage of the residents work in the greater community and have the natural supports to provide additional "eyes and ears." Active family involvement in the community offers additional safeguards. Those residents less able to communicate are loved and supported by residents who have greater ability to communicate and who would "have their back" in case of any potentially abusive situation. No one within the community tolerates any amount of abuse or neglect. All residents have their own lock and key and there is an optimal balance of safety and freedom.

We feel strongly that the HCBS funding is perfectly well suited for people with severe developmental disabilities like my brother and offers the only real opportunity to allow him to live in a community setting.

Regarding aspects of the definition of "integrated community" that specify that no common meals should be provided: people with intellectual disabilities often thrive best with a degree of structure, and so scheduled mealtimes are an asset, offering a chance for socialization and an understanding of times of the day and a normal daily rhythm. In my brother's planned residential community, any individual who does not wish to dine in a group with the rest can prepare meals in their own kitchen, or request a boxed meal to be enjoyed at any time of day. This is an optimal arrangement that most residents take full advantage of. My brother prefers the common meals provided in the dining room and is healthy and well-fed. Mealtimes are his favorite time of the day.

HCBS funding should not be targeted for only the higher-functioning segment of the DD population who are the most independent, and who are self-sufficient enough to live in their own apartments in the larger community. The higher-functioning population who

are able to organize their own community based social activities are very fortunate. But people on the lower-functioning end of the spectrum should not be disqualified from community-based funding merely because they prefer a setting which offers opportunity to live and socialize with people whom they consider their peers. Coincidentally, my brother's peers may or may not share a diagnosis. That is irrelevant. A person should have the choice of living with the people they are most comfortable with, even if they happen to have a similar disability. They are not segregated because they have full access to the larger community.

Consider *Larken v. State of MI, et al.* which states: "...the state's policy of forced integration is not protecting the disabled from any forced segregation; rather, the state is forcing them to integrate based on the paternalistic idea that it knows best where the disabled should choose to live." There is no one-size-fits-all definition of a community and no litmus test to discern what constitutes a community. Again, no Secretary should have the power to take away an individual's right to choose a community setting that is right for them just because they have an intellectual disability.

In summary, people with intellectual disabilities should have the freedom to choose the level of integration appropriate for their needs and to live with whom they wish, regardless of diagnosis. The specific characteristics of the community they choose should never disqualify people with intellectual disabilities from receiving HCBS funding.

Sincerely,
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