

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

RE: File Code CMS-22296-P

To Whom It May Concern:

Thank you for issuing this strong regulation concerning the Home and Community Based Service (HCBS) waivers. The Centers for Medicare and Medicaid Services (CMS) are to be commended for taking such important positions on items like what is considered home and community settings, requiring the use of person centered planning, and making the waiver process more transparent to interested stakeholders.

These comments are made on behalf of Disability Rights Texas (DRTX), the designated Protection and Advocacy entity in Texas. Our mission is to advocate for, protect and advance the legal, service and human rights of Texans with disabilities.

Of particular interest to the DRTX is the discussion of what is or is not a home or community setting. CMS has recently taken strong positions on what settings are home and community in order to qualify for the use of HCBS funding, and that continues in this regulation. By definitively stating what environments are not a home or community setting, CMS will help ensure that the intent behind HCBS funds is fulfilled by providing services in the most integrated settings. Being upfront that building smaller homes on the grounds of institutions and creating disability specific housing complexes or communities are not considered home and community will help end the troubling attempts to use HCBS funds to create these inherently non-integrated settings to live and/or receive services.

In Texas during the current legislative session, the Assisted Living Facility (ALF) lobby has attempted to encroach both on the Community Based Alternatives (CBA) 1915 (c) Medicaid waiver program and the available tax credits for housing/facility developers. At one point this year, the ALF wanted to have CBA waivers allocated to the facility and to capture a specific high amount of tax credit dollars to develop new facilities. It is critical to specify certain requirements for where services can be provided that include features like in an independent living setting in an apartment. A Texas legislator, in presenting proposed legislation, said the nursing home industry was seeking a new service model due to the vacancy rate in NFs. In our state, the ALFs have sought to bypass CBA rules and simply have ALF licensure apply. That licensure would eliminate many current requirements that help make the CBA ALF apartments be more independent and home like settings. Based on many objections raised by Texas disability housing and community services advocates, neither of these terrible provisions in proposed legislation are moving forward at this moment. However, a special Session has been called and newly filed budget bills may be amended. We believe the ALF industry will continue their efforts for years to come and we must be vigilant.

We support increasing regulations that ensure that individuals in ALFs have a lease, a key, can have guests and other features that align with person centered/independent living and Fair Housing Act regulations. We encounter individuals who are being kicked out of ALFs, usually because they speak up when something is not as it should be or they may have other conflicts related to their disability that are not reasonably accommodated. We ask CMS to ensure appropriate due process regulations for individuals using HCBS funds while living in an ALF.

Below is the language adopted for the Texas Community Based Alternatives (CBA) 1915 (c) Medicaid waiver regarding assisted living facility apartment requirements. If an ALF resident does not want to have a kitchen, the Texas CBA rules allow for that. See below:

CBA Handbook - contracting section, DADS website

<http://www.dads.state.tx.us/handbooks/cpalrcs/B/index.htm#r146.13>

§46.13 Housing Options

(a) Setting. A facility must specify in the contract the type(s) of setting(s) it uses to provide assisted living services according to the following guidelines:

(1) Assisted living apartment. An assisted living apartment setting is a living unit that is a private space with living and sleeping areas, a kitchen, a bathroom, and adequate storage space. The bedroom must be single occupancy, except when the participant requests double occupancy in writing. The living unit must have private kitchen and bath facilities.

(A) Size. Assisted living apartments must have a minimum of 220 square feet, not including the bathroom. Current contracted assisted living apartments that do not meet the square footage requirement may remain at their current size unless the apartment is remodeled. Remodeling includes:

(i) the construction, removal, or relocation of walls and partitions;

(ii) the construction of foundations, floors, or ceiling-roof assemblies;

(iii) the expansion or alteration of safety systems, including:

(I) sprinkler;

(II) fire alarm; and

(III) emergency systems; or

(iv) the conversion of space in a facility to a different use.

(B) Kitchen. The kitchen is an area equipped with a sink, refrigerator, a cooking appliance, adequate space for food preparation, and storage space for utensils and supplies. The cooking appliance must be a stove, microwave, or built-in surface

unit. The cooking appliance must be able to be removed or disconnected.

(C) Bathroom. The bathroom must be a separate room in the individual's living area with a toilet, sink, and an accessible bath.

In Texas we have also had providers/organizations such as "Down Home Ranch" and "New Danville" seek to create HCBS funding mechanisms for their self sustaining "master planned" congregate campuses, ranches, neighborhoods or gated communities that we strongly believe continue to separate and segregate individuals with developmental disabilities. Please clearly disallow these living arrangements in the final regulations. These providers seeking HCBS funding usually do not understand community integration values and that HCBS waivers are alternatives to living in segregated settings. They also are comfortable with openly recruiting individuals who fit their desired profile rather than being inclusive of all levels of support needs, which is not consistent with our HCBS programs for individuals with intellectual disabilities. Some even attempt to sell their programs as "integrated," but they do not integrate individuals with disabilities with neighbors of their choosing who do not have disabilities.

In preparing our comments, one individual with disabilities whose input was received said, "If the purpose of these waiver programs is to help reduce the number of people living in institutions, which I believe is the overall goal, and to help them integrate into the community, then it makes no sense to try to use these programs in order to create more institutional options for the individuals involved. Just the opposite, we need more options for independent living."

In addition, one of the most important parts of this discussion of home and community is that the regulation rightly states that HCBS waiver funds are used for more than just where a person lives. Waivers fund a number of other services that should also be performed in the most integrated setting possible such as employment services and other day services. If any consideration is given to continuing or "grandfathering" services in existing waiver service settings, only make it for the time of the next waiver renewal cycle. Sheltered employment and day habilitation services perpetuate segregation and marginalize citizens with disabilities.

We strongly support having choice regarding where one lives and who provides the services, without having those housing and services inextricably connected.

In Texas, family supports, respite, and foster/companion care are greatly at risk in both Medicaid waivers and non-Medicaid funding. Respite definitions are becoming more restrictive in both the waiver renewals approved by CMS and in the policy directions set in rules and provider manuals - especially in the developmental disabilities programs. Let's be clear that respite (a temporary break from caregiving) is needed by caregivers whether paid or unpaid. There has been recent consideration by the state to disallow respite to any paid caregiver, even part time paid family caregivers, in the Community Living Assistance and Support Services (CLASS) waiver. We hope our discussions with state officials will prevent such a decision. Foster Care (FC) rates in the Home and Community Services (HCS) waiver are proposed to be cut as are in home Supported Home Living

(SHL), but not group home rates. This may incentivize providers to push more costly and more restrictive group home living options rather than SHL or FC. The non-Medicaid funds for small In Home and Family Support services are disappearing along with the flexibility they provide to individuals and their families. Please keep a look out for these type waiver amendments and make sure that stakeholders have been heard in the process, both by state officials and by CMS.

More than once, CMS has approved state requested waiver amendments that have been objected to and/or not vetted in the renewal process. Budget decisions in our state and other states will result in states' requests for amendments to several waivers. Please consider not only the health and safety of program participants, but whether they will be able to integrate and participate fully in their communities. State budget cuts and subsequent waiver amendments to reduce supports and services must not leave individuals in waivers homebound.

The recognition that plans for a person with a disability should not be made without the involvement of the person has been increasing in recent years, and CMS recognizes this important trend in this regulation by requiring the use of person centered planning when developing the uses for HCBS waiver funds. The importance of having this concept fully recognized in the federal regulation cannot be understated and will hopefully lead to its use in a number of other settings.

Finally, CMS has made some important improvements in the administration of the HCBS waivers through this regulation. By not allowing a new waiver or substantive changes in an already existing waiver to take effect until the waiver has been approved by CMS will help ensure that the waivers fulfill the mandate of the HCBS waiver program. In addition, the new transparency requirements will help interested stakeholders know and comment on changes being considered and makes what is now a very secretive and closed process much more open to the public as a whole. Lastly, we applaud CMS for seeking input on new ways to ensure compliance with the provisions of the HCBS waiver.

Again, CMS should be commended for the many important improvements to the HCBS waiver program in these regulations, and I hope to see them when the final regulation is issued.

Sincerely,

Susan Murphree
Senior Policy Specialist
Disability Rights Texas, 7800 Shoal Creek Blvd. #171 E, Austin, Texas 78757
512-407 2754 (p)
512-323-0902 (f)
512-454-4816 (tty)
www.drctx.org