CPSD Recommendations to CMS - Implementation of HCBS Waiver Regulations

August 19, 2014

I. Recommendations on Non Residential Settings Sub-Regulatory Guidance

CMS should clarify and specifically include the following in the sub-regulatory guidance:

A. The need for states to offer non-disability specific setting options:
   i. For each type of HCB non-residential service a state offers, the state must offer non-disability specific setting options. Since each HCBS service is distinct and non-duplicative, offering a non-disability specific setting option through one service (e.g. supported employment) should not eliminate the need for a state to offer at least one non-disability-specific setting option for another non-residential service (e.g. prevocational services or day services). No state should be permitted to receive HCBS funding for a non-residential service if the setting options available for that service are limited to disability-specific settings.
   ii. States are not required to offer “disability specific settings” so long as there is choice of settings available to waiver participants. In other words, all settings a state offers could be “non-disability specific settings” as referenced in 79 FR 3030.

B. Non-Residential Settings for HCB Employment Services (Prevocational Services, Supported Employment Services, Career Planning, etc.):
   i. HCBS recipients receiving employment services must be afforded a choice of a variety of mainstream, integrated employment opportunities and activities that
advances competitive employment in integrated settings which do not isolate HCBS recipients from the broader community.

ii. HCBS services cannot be delivered in provider-owned settings where the primary purpose of the setting is to deliver employment services (e.g. habilitation and/or rehabilitation) to people with disabilities. Provider-owned employment settings include any setting a provider may lease, operate or have an ownership interest in (e.g. social enterprises operated by a provider organization whose primary mission is to provide employment services and opportunities to people with disabilities or an organization with a legal relationship to a provider organization that has this primary mission).

iii. An HCBS recipient may receive employment services in a setting that is owned by an HCBS provider only if:
   a. The primary purpose of the setting is not delivering employment services to people with disabilities;
   b. The provider of employment services for the HCBS recipient is a different provider than the provider that owns the setting in which the HCBS recipient works;
   c. People without disabilities (who are not staff paid to provide employment services) make up at least 88% (natural proportions) of the people typically present in the setting.

C. Non-Residential Settings for HCB Day Services:
   i. When HCBS recipients may receive non-residential services that are not employment-focused, they must be afforded a choice of a variety of daytime activities in integrated settings that do not isolate HCBS recipients from the broader community.

   ii. Non-residential HCB day services for working-age people with disabilities are distinct from day services for seniors delivered through HCBS programs. While both should meet the HCB setting standards outlined in the rule, day services for working-age people with disabilities warrants the adoption of higher expectations in relation to meeting the standards, given the integration mandate in the Americans with Disabilities Act as interpreted through the Olmstead decision. Since the ADA and Olmstead decision apply specifically to individuals with disabilities, the need to prevent segregation, not just isolation, is critical, as is the need to promote and offer services in fully integrated settings as a matter of policy. Additionally, CMS has taken a policy position that HCBS should promote integrated, competitive employment for individuals with disabilities, through its September, 2011 Informational Bulletin, and it is assumed that CMS did not intend this expectation to apply to seniors receiving HCBS. The combined impact of these disability-focused policy expectations necessitates the creation of definitive guidance on non-residential HCB day services when these are provided to working-age HCBS recipients with disabilities.
iii. In order to avoid many HCBS recipients with disabilities experiencing little or no increased access to, and opportunities to participate in, the life of their communities, including integrated employment opportunities, it is essential that CMS does not permit congregate day service settings for individuals with disabilities. Permitting such settings will likely result in the large scale transition of HCB recipients with disabilities, currently receiving facility-based prevocational services, to congregate day services. This does nothing to address isolation from the broader community or lack of access to integrated employment and such an outcome cannot be acceptable.

iv. In meeting the HCB standard that requires settings to support opportunities to pursue and work in competitive, integrated settings, day services that are delivered in settings that are not congregate and/or facility-based can advance such opportunities for working-age HCB recipients with disabilities. Day services delivered in fully integrated settings can give HCB recipients the opportunity to engage in career exploration, learn and maintain travel skills, network with members of the broader community who can be conduits to employment opportunities, develop skills and routines that support success in employment, and utilize community resources that contribute to an individual’s transition to integrated employment. Settings that are congregate and disability-specific simply cannot offer these benefits and opportunities for working-age HCB recipients with disabilities.

D. Non-residential day and employment service settings that are HCB will ensure these types of experiences for HCBS recipients:

E. Routine and frequent access to activities in the greater community which support the intended purpose/outcome of the service (detailed in service definition) and the goals/outcomes of the individual service recipient.

i. Participation in activities taking place in ordinary community venues (not owned, operated or leased by HCBS providers; such as fitness facilities, community centers, recreation centers, libraries, community colleges, religious centers, etc.) during times these venues are open to the general public and participants include community members without disabilities who do not receive HCBS (and who are not paid HCBS staff).

ii. Routine and frequent opportunities to access services available to the general public including those not receiving Medicaid HCBS services. Two employment examples: (1) an HCBS recipient who wishes to pursue employment is assisted to access and participate in services at a Job Center/One Stop where other individuals (who don’t have disabilities or don’t receive HCBS) seeking employment go to access services; (2) an HCBS recipient who wishes to develop skills for employment participates in an internship or apprenticeship at a community business, or volunteers doing something that will help build skills and experiences relevant to his/her employment goal.
iii. Readily available support for getting to activities and opportunities in the greater community, without restrictions on when or how often an individual may use this support.

iv. Non-residential services in settings that comply with HCBS standards, including prevocational and day service settings, must be delivered by a provider that has sufficient staff, property trained and readily available (without undue delay or wait time) to assist individuals to access other services that can help them obtain and maintain competitive employment in integrated settings. Any provider not having such staff should not be considered to operate Medicaid HCB settings that meet the criteria established by the regulation, namely that HCB settings provide opportunities to seek employment and work in competitive integrated settings.

v. Day supports, including transportation, are individually-planned and delivered; group activities would not be generally appropriate unless individually-selected.

vi. The type and range of activities—including educational, recreational, familial, social, faith-based—as part of a meaningful day should be comparable to those in which non-disabled persons of similar age routinely engage.

vii. Sufficient supports must be provided to allow a person to engage in a meaningful day in integrated settings outside the home for the maximum number of hours consistent with the individual’s abilities, interests and preferences.

viii. Services must facilitate contact and interactions with community members without disabilities and those not receiving HCBS in all community settings where a person spends his or her day.

ix. Activities supported through non-residential HCBS must be designed to maximize independence (social, interpersonal and economic), autonomy, and self-direction.

x. Employment services must provide contact with non-disabled peers in all employment locations: workplace and work environment (e.g.: lunch room).

xi. Services must be provided in mainstream employment settings and not in facilities.

xii. Employment must be the primary goal of services.

xiii. Employment services and job placement are individual-planned and delivered; customized employment but not mobile crews and enclaves.

xiv. The terms and conditions of employment—such as wages, benefits, supervision, advancement, and tenure—where employment services are provided must be comparable to those offered to non-disabled workers.

xv. Sufficient supports (like supported employment) must be provided to allow each individual to work the maximum number of hours consistent with the individual’s abilities and preferences.
xvi. Flexible individualized planning around employment choices

F. Non-residential day and employment service settings that are not HCB, and are settings that isolate HCBS recipients from the broader community will typically be characterized by the following:

i. Transportation, if provided as part of HCBS involves use of special vehicles transporting primarily HCBS recipients to and from the service setting;

ii. The service setting is located on the outskirts of a geographically defined community, in areas where publicly accessible community venues are not nearby (e.g. industrial parks);

iii. A single service setting is typically utilized, meaning HCBS recipients spend much of their service hours in a single building (or on single property with multiple buildings on it);

iv. If multiple service settings are typically utilized, the majority are disability-specific settings;

v. If HCBS recipients are supported in community settings, this will typically involve groups of HCBS recipients (4 or more) using the settings;

vi. If HCBS recipients are supported in community settings, this will typically involve using these settings at times when it is not typical for other members of the wider community (non-HCBS recipients) to be using these community settings. Examples would include: (1) swimming at a public pool at a time when the pool is not typically available to and used by other community members and may be reserved specifically for people with disabilities; going bowling at a time when other community members don’t typically use the bowling alley and at a time that may be specifically reserved for use by people with disabilities or the provider agency supporting them.

II. Recommendations Regarding Transition Plans Submitted by States

A. There is still insufficient guidance for states regarding the process for development of acceptable transition plans, particularly the range of strategies a state can and should be using to bring settings into compliance and to ensure compliance is maintained over time. We encourage CMS to publish more guidance and tools as soon as possible.

B. For states submitting plans, we encourage CMS to actively work with each state to strengthen and improve their original submission, consistent with the public comments received, prior to CMS approving the plans.

C. No state’s plan should be approved if they do not document the various types of settings in which each HCB service is currently provided, along with the method and results of the evaluation of each type of setting currently used. Some states appear to misunderstand the requirements and are focused on the service categories rather than the settings in which these services are delivered.
D. Where states submit a plan to develop a transition plan, rather than the transition plan itself, it is essential that CMS require the following as part of approving these types of plans:
   i. A clear timeline for developing and submitting the actual transition plan to CMS with a commitment to regular updates on progress made available to stakeholders and CMS;
   ii. Additional mandatory public comment periods on the actual transition plan once developed;
   iii. Requirement that states catalogue and respond to the comments received on the actual transition plan, and incorporate these comments into the final transition plan submitted to CMS;
   iv. A clear timeline for bringing settings into compliance which is distinct from the timeline a state may submit for evaluating settings and creating the transition plan.

E. In the absence of published sub-regulatory guidance on non-residential settings, we recognize that many states may submit initial transition plans that do not address non-residential settings. We strongly encourage CMS to issue a memo as soon as possible which outlines clear expectations for states to revise their transition plans and address non-residential settings once the sub-regulatory guidance is published. These expectations should include:
   i. A required public comment period focused on the state’s plan and timeline for evaluating non-residential settings;
   ii. A required public comment period for the actual transition plan amendment focused on non-residential settings;

F. We strongly encourage CMS to closely scrutinize each states’ efforts related to public comment to ensure adequate notification and outreach to stakeholders has been done, particularly with regard to HCBS recipients and their allies who may not have access to the internet, may have limited or no reading skills, may need information in alternative formats (including plain English), or may lack the ability or supports to independently submit comments.
   i. If states submit a summary of public comments received that suggests relatively few public comments were received in relation to the size of the state’s HCBS programs, CMS should do additional review of the state’s efforts related to soliciting public comment and require states to undertake additional public comment periods and strategies if the initial effort did not result in meaningful participation and public comment.

G. Transition plans must be required to address the development of provider capacity to deliver HCB services in integrated, non-disability-specific settings, given that such settings must now be offered to HCBS recipients and this creates the likelihood that there will be a significant increase in the number of HCBS recipients who will choose to receive HCB services in integrated, non-disability-specific settings.
H. In order for meaningful systems change to occur as a result of the new regulations, we support CMS permitting state transition plans that may take more than five (5) years to implement if such plans include a commitment(s) to completely phase out isolating settings (e.g. sheltered workshops, facility-based day programs; group homes) and those settings are currently used by a large number of HCBS recipients in the state. Such flexibility is likely to encourage states with particularly large HCBS systems to take more bold and impactful actions to meet the full spirit and intent of the new regulations, which they otherwise might not take given the five (5) year timeframe. We do not support extensions beyond five (5) years if states are not committed to complete elimination of isolating settings and have not made substantial progress in the first five (5) years as evidence of their commitment to this outcome.

III. Recommendations on Person-Centered Planning
A. A fundamental principle underpinning the new regulations is that HCBS recipients must be supported, both in the person-centered planning process and by HCB service providers to choose their own activities and control their own schedules. State transition plans should not be approved unless they clearly and adequately address how HCBS planning and service provider practices will be brought into line with this fundamental principle.
B. The person-centered planning process must ensure that providers of services included in the ISP/Plan of Care work with individuals to create individualized, person-centered schedules. A process for developing truly individualized schedules and supports for these schedules should occur at the start of service and then should be revisited and updated on a regular basis over time.
C. The party responsible for facilitating person-centered planning and writing the ISP/Plan of Care must monitor service provision to ensure truly individualized schedules, based on an HCB recipient being offered a range of options and choices in settings that meet the new HCB standards, are being developed and implemented by HCB service providers.
D. Person-Centered Planning with individuals with disabilities must begin with a presumption that people with disabilities can do the same things that people without disabilities do, in the same places that people without disabilities do these things. To this end, the person-centered planning process must be focused on:
   i. Options that make use of the most integrated settings available – those being non-disability-specific community settings where individuals have maximum opportunity to interact with, form relationships with and receive natural supports from other members of their communities who do not have disabilities and who are not paid disability service staff.
   ii. Options that start with a presumption that the most integrated setting appropriate (i.e. the most integrated setting in which an individual can be effectively served) is a non-disability-specific community setting. HCBS
recipients must be afforded the choice of receiving employment services in a variety of competitive, integrated employment settings (and where an individual receives non-employment services, the individual must be afforded the choice of receiving these services in a variety of mainstream, non-disability-specific community settings).

iii. Options that are effective in meeting the intended goals and outcomes associated with each HCBS service, individualized to reflect the personal goals and outcomes of each HCBS recipient.

iv. Options that offer people as personalized and customized supports as possible rather than options that involve relatively small numbers of staff supporting relatively large numbers of individuals with disabilities. We recognize that individuals with disabilities can be offered more personalized and customized supports when services are delivered in non-disability-specific community settings and maximum service dollars can be invested in service delivery, rather than maintaining separate buildings or facilities.

E. All person-centered planning must adequately address transportation to support the feasible use of non-disability-specific settings, community options and choices described above by all HCBS recipients. No state should be permitted to maintain HCBS-funded transportation that is exclusively or primarily tied to, or ultimately invested in, disability-specific settings. Access to setting options which meet the new HCB standards and offer personalized and customized supports should not be conditional on an HCB recipient independently financing and using transportation. States should be required to decouple transportation and residential services, and to develop individual transportation plans for each individual as part of the person-centered planning process.

IV. Recommendations on Conflict of Interest

A. Consistent with the new regulations, we recommend that CMS require states to develop and issue clear and complete conflict of interest guidelines for all participants in a person-centered service planning processes. This should include service providers, parents, guardians and others who may be involved in the planning process with an individual.

B. CMS should require states to adopt policies which permit the exclusion of service providers from certain aspects of the person-centered service planning process in order to address situations where significant conflict of interest exists so as to ensure:

   i. An individual always is afforded meaningful choice of providers and can choose to change providers at any time without undue influence from an existing provider;

   ii. An individual has opportunities to freely discuss in confidence with his/her case manager, care manager, nurse, or support broker any concerns or issues regarding his or her service providers; and
iii. An individual is afforded the opportunity to freely decide his/her goals, without undue influence from one or more providers who may stand to benefit if certain goals or outcomes are chosen over others.

V. Recommendations on Controlling of Personal Resources
   A. It is essential that state HCBS programs provide education to working-age HCBS recipients on the benefits of work, access to work incentives counseling and assistance to access other public systems that can assist with obtaining and maintaining competitive, integrated employment.
   B. States should be required to ensure that all HCBS providers have staff trained in supported decision-making, particular to financial literacy, so that arrangements which allow a third-party to control an HCBS recipients personal resources are only used in exceptional circumstances.
   C. CMS must ensure that state HCBS programs ensure - through policy and practice - that earnings from work remain within the control of the HCBS recipient. CMS should not allow state HCBS programs to adopt policies or practices that promote or require that an HCBS recipient agree to turn over control of his/her earned income to a Representative Payee.
   D. Residential providers should not be permitted to also serve as an HCBS recipient’s Representative Payee.