Response to OPWDD HCBS Settings Transition and Implementation Plan

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INTRODUCTION

In January of this year, the Centers of Medicare and Medicaid Services (CMS) released their final rule on Home and Community Based Services (HCBS). This rule, which took effect on March 17, 2014, establishes new requirements for HCBS for Medicaid funding for long-term services and supports (LTSS) and institutes new rules for what qualifies as a community-based residential setting. The goals of this rule are to prioritize the integration of people with disabilities into the community, enhance their quality of life, and to increase protections for individuals receiving services. All states are required to assess their current service systems, determine which of their existing systems meet the new requirements, submit a transition plan, and ultimately comply with the new HCBS regulations within the next five years.

The Office for People with Developmental Disabilities (OPWDD) Waivers that are up for renewal are required to comply with the HCBS rules; this includes the OPWDD 1915(c) waiver which will renew on October 1, 2014 and the OPWDD 1915(b) waiver which the Office plans to voluntary renew in 2015.

OPWDD released their HCBS Settings Transition Plan in early 2014, these comments are in response to that released plan. These comments are an abbreviated, OPWDD specific, version of our full comments submitted to the New York State Department of Health in response to the State's Transition Plan. The full comments are located on NYAIL's website:
http://www.ilny.org/programs/cfc-tap/resources-and-advocacy-tools

BACKGROUND

The Supreme Court decision in *Olmstead v. L.C.,* 527 U.S. 581 (1999) applied the integration mandate of Title II of the Americans with Disabilities Act of 1990 to LTSS. The decision affirms that services must be provided in "the most integrated setting appropriate to the needs of qualified individuals with disabilities," which, for many, means a fully integrated home in the community. The definition of "home and community," adopted by the State is crucial to New York State's compliance with the *Olmstead* decision.

In October of 2013, New York released their long-awaited Olmstead Plan, detailing how the State intends to comply with the *Olmstead* decision. This plan includes a ten percent reduction in the State's long-term nursing facility population with the intent to accomplish this via transitions into community-based settings over the next five years. The definition of what constitutes a community-based setting, and OPWDD's ability to comply with the Federal rules, will have a significant impact on people with disabilities who will be transitioned as a result of the Olmstead Plan.

APPLYING HCBS RULES

Below are the three main characteristics that the Disability Rights Community advocates that settings must embody in order to be considered integrated and community-based:

I. People with disabilities should not be required to accept or comply with services to get and/or maintain housing.

People without disabilities do not have their housing conditioned on whether or not they accept services. Therefore, housing rights for people with disabilities should be entirely separate from services that a person may or may not want, need, or desire without any conditions related to services. CFC services are delivered regardless of type or severity of disability and providing housing based on the aforementioned circumstances would be discriminatory.

II. People with disabilities should be able to maintain their legal tenant and housing rights and still receive the services and supports they need.

People without disabilities are afforded certain universal protections under tenant-landlord law, including safety measures regarding eviction. Therefore, people with disabilities should also be able to legally uphold the same rights, protections, and responsibilities. Essentially, if a person with a disability pays his or her rent on time, the individual should be allowed to stay in their housing per terms of the lease.

For a setting to be community-based, the owner or operator of the setting cannot evict a person because he or she refused to accept a particular service. This requirement is often referred to as "Housing First," and has received widespread acceptance as a method that not only promotes independence, choice, and responsibility, but also results in significantly better outcomes than programs that make housing contingent on compliance with treatment.

For all people with disabilities, housing should not be contingent on acceptance of a particular form of service provision. If a person is not able to refuse service provision without the threat of also losing housing, then the individual loses all meaningful choice, control, and autonomy in the planning process. Effectively, it would allow service providers to utilize HCBS funds for settings that are fundamentally institutional in nature and provide individuals with disabilities with no option other than finding and moving to new housing.

III. People with disabilities should be able to direct fundamental decisions that affect their lives and get the services and supports they need.

People without disabilities, wherever they reside, have a right to the following and as such, the same rights must be afforded to people with disabilities regardless of housing:

- A lease under the State's landlord-tenant law protecting against illegal evictions;
- Privacy in sleeping and living units, with a lockable entrance;
- Choice in sharing units with the person’s roommate, only if the person with disability freely and knowingly wants to share;
- Freedom to decorate sleeping and living units in any manner desired;
- Control over their own schedules and access to food at any time;
- Freedom to have visitors of their choosing at any time; and
- Physical accessibility.

Settings

In order to successfully transition OPWDD services, the Office must assess the programs currently provided under the 1915(c) waiver. Undoubtedly, some settings will already be acceptable while others will need to be modified or discounted completely. It is vital that no program be assumed to be compliant and that all settings are assessed in a thorough, unbiased manner. Each program must be evaluated on the level at which services are received in order to assess eligibility. In addition to OPWDD - providers, service recipients, self-advocates, and advocate groups should also have the opportunity to review the compliance of these programs.

Per the CMS final rules, HCBS-compliant settings must include the following characteristics:

(i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.

(ii) The setting is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.

(iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.

(iv) Optimizes but does not regiment individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

(v) Facilitates individual choice regarding services and supports, and who provides them.

While some OPWDD settings already meet the requirements of HCBS compliance, many do not. To accomplish compliance, we suggest the Office complete a comprehensive review by completing the following steps:

1. Issue surveys to providers to evaluate their own settings by type and location;

2. Complete an in-person assessment of a representative sample of the 1915(c) providers and settings;

3. Issue surveys to providers to evaluate their own settings by type and locations (excluding service provided in the waiver participant's own home or family home);

4. Provide a survey to waiver participants, guardians, and other stakeholders to evaluate and give input on provider settings by type and location;

5. Summarize all HCBS and areas of compliance and non-compliance;

Because the Disability Rights Community has been at the forefront of community integration efforts for decades, OPWDD should contract with disability-led organizations to help conduct these reviews. Specific examples are Independent Living Centers, the Self-Advocacy Association of New York, and the Mental Health Empowerment Project.

Furthermore, after completing in-person assessments of a representative sample of the 1915(c) providers and settings in order to create a transition plan; the OPWDD should then perform in-person assessments in *all* 1915(c) providers and settings before the transition period expires. After the transition is complete, OPWDD should continue to review providers and settings to evaluate locations, characteristics, and other institutional or isolation qualities.

SECTION 1915(C): MEDICAID HOME AND COMMUNITY-BASED SERVICES WAIVER

New York's 1915(c) Home and Community-Based Services waiver permits the State to provide Medicaid consumers with home and community based services so that they may avoid unnecessary institutionalization. OPWDD services must be assessed before deemed compliant with HCBS rules. The following is a review of the OPWDD waiver services that require modification before they can be qualified as HCBS.

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Respite

Respite is a service that provides temporary relief to caregiver. Respite services can be provided in an individual's home, which is classified as unstructured respite, or be provided in a congregate setting, this is classified as structured respite. Since unstructured respite services are provided in an individual's home, this service is consistent with the federal HCBS setting rules. Issues around respite are within structured respite as services are provided in an institutional-like setting, including Individualized Residential Alternatives (IRAs), which are often referred to as group homes, and Intermediate Care Facilities (ICFs). If respite is provided in an IRA, an individual must have the liberties enjoyed by nondisabled persons. If an individual is staying overnight, they must be able to choose their roommate or have their own room, have a short-term agreement in place (in lieu of a lease), be able to have visitors, and eat when they choose. ICFs will never be considered an integrated community settings as per CMS and must not be considered eligible.

NY OMRDD Comprehensive

Day Habilitation

Per the CMS rules, day habilitation services must be provided in a setting the meets the HCBS requirements and may not be provided in an institutional or institutional-like setting.
Currently many agencies, including OPWDD, provide facility-based day habilitation in a non-residential setting or a setting similar to a sheltered workshop. This type of setting unnecessarily segregates people with disabilities and does not adequately teach them the socialization and adaptive skills core to this service. To comply with the HCBS rules, day habilitation needs to be provided in an integrated community setting that cultivates an individual's independent living skills. We recommend that the State use the day habilitation programs at ILCs across the New York as a model for effective community-based day habilitation services.

Prevocational

Per CMS rules, pre-vocational services must be provided in a setting that meets the HCBS requirements. Pre-vocational services teach non-job-specific concepts that will help an individual transition into and be successful in a work environment. Currently, most prevocational programs are structured and take place in a congregate setting, and heavily refer to sheltered workshops. New York is required to transition these services into community-based compliant settings that promote independence and provide an individual with the opportunity to interact with people without disabilities, engage in community life, and have choice in the services they receive what type of jobs they are referred to.

Residential Habilitation

The HCBS setting rules state that habilitation services must be provided in a home and community based setting and may not be provided in an institutional or institutional-like setting. In some cases, residential habilitation takes place in a person's own home and is already classified as a HCBS. That being said, residential habilitation is also provided in IRAs (group homes). The vast majority of IRAs are simply converted ICFs, and as mentioned in pervious sections, ICFs will never qualify as home and community based. In order for the State to provide residential habilitation services to individuals living in IRAs (where many individuals with developmental disabilities live) significant modifications must be made to the structure and culture of the setting. This includes a choice of roommate, written lease, freedom to come and go as the individual pleases, freedom to have meals at any time, and all other opportunities available to an individual who does not receive Medicaid services in their home.

Respite

As addressed in previous the respite section, structured and unstructured respite can qualify as home and community based under the CMS setting rules if the service is provided in a qualified setting. For unstructured respite, this setting would the home or family home of the individual. Structured respite may be provided in a setting that offers an individual the same liberties available to a nondisabled person and meets the requirements set forth in the HCBS rules as described above.

Supported Employment

Supported employment has the ability to and has helped many people with disabilities secure integrated employment. That being said, there are some practices within supported employment that are not in line with CMS' HCBS rules. For supported employment to qualify as a HCBS services and to draw down Medicaid funding, it must provide consumers with the opportunity for competitive and integrated employment and the ability to choose between available jobs. "Creaming" is a practice within supported employment in which employers hire people with less significant disabilities instead of individuals with severe disabilities, those for whom the program was created. The interaction between sheltered workshops and supportive employment is also an issue. Many agencies that run a supportive employment program also run sheltered workshops. These agencies often refuse to place a current sheltered workshop employee into supported employment until their work meets an arbitrary level of productivity. This forces an individual to keep their current job, preventing them from having real choice. In addition, many supportive employment programs work off a "one-job-fits-all" model. When a job becomes available, they offer it to the person at the top of the list, if that individual denies the job they are dropped to the bottom of the waiting list. This practice denies a consumer their independence in making life choices, is inconsistent with the person centered planning requirement, and directly contradicts the HCBS rules. As

the State develops their Transition Plan, we recommend it take a closer look at supportive employment practices in each program before deeming the program HCBS compliant.

Consolidated Supports and Services

The consolidated supports and services is a program offered through OPWDD that allows an individual to direct their own services. This program will be discontinued after October 1, 2014 in order to meet federal Medicaid guidelines and streamline self-direction services. A requirement of this change is that all Medicaid fundable, self-directed services must be aligned with a HCBS waiver service and, in turn, HCBS compliant.

Provider-Owned and Controlled Settings

Provider-owned and controlled settings are a contentious issue in waiver programs, most notably as IRAs are a common environment in which services are provided. These settings have the potential to comply with the HCBS rules if they adhere to strict regulations so as not to undermine the definition of integration and community-based setting. First and foremost, the individual must be presented with a true choice. The alternative to living in a provider-controlled setting should not be a significant decline in standard than the provider-controlled unit.

For example, if the provider-controlled setting is in a nice, safe neighborhood but alternate private housing is only available in a crime-ridden, derelict area, the individual does not truly have a choice of where to live. Similarly, if a person cannot afford a private residential unit or get adequate services and supports in that setting, the State should not be able to claim the individual was given a choice. To assure compliance with this, individuals in provider-controlled settings must be offered a real choice and opportunity to live in a private, residential unit with adequate services and supports. Consumers must be educated and aware of this option, and presented with the choice on a yearly basis. OPWDD should not be complacent in this matter.

If an individual is to live in an IRA or other provider-controlled setting, he or she must be presented with the following: (1) the option to live in another, non-provider controlled setting in a comparable neighborhood; (2) the option of whether or not to receive services in the provider-controlled setting; (3) choice of providers from which to receive services, not forced to receive support from provider that controls housing; and (4) protection from discrimination or eviction if choosing not to receive services from provider that controls housing.

The CMS “Community Based Settings” Fact Sheet adds that States “have the responsibility for ensuring that individuals have options available for both private and shared residential units within HCBS programs.” The rule further clarifies that an individual’s needs, preferences, and resources are relevant to his options for shared versus private residential units. Provider owned

or operated residential settings will be responsible to facilitate individuals having choice regarding roommate selection within a residential setting.

IRAs and other provider-owned settings that do not meet HCBS regulations must be modified. A workgroup should be established to address these issues and based on: (1) what steps need to be taken to modify those settings which did not meet HCBS requirements; and (2) a detailed timeline to carry out aforementioned steps. This workgroup must also have ample representation from disability rights advocates and those individuals who will be receiving services in HCBS-settings. If IRAs and other provider-owned settings cannot meet the minimum HCBS-regulations, then they must not be considered community settings. This is imperative as it is possible that some IRAs and provider-owned settings may be HCBS-eligible, while others are not. As stated before, the State must assess each environment independently and not make a sweeping generalization about these sites.

Quality Assurance Measures

We strongly suggest that OPWDD adopt quality assurance measures in their Transition Plan. Without checks and balances by independent parties, transition activities can be performed without accountability. It is imperative that the progress of the transition is documented, held up to pre-determined standards, and accessible to the public. We recommend regularly publishing the following to the OPWDD website:

- All deliverables, including progress reports, completed plans, implementation reports, status updates
- Updated list of compliant and non-compliant HCBS settings
- Any modified rules and policies

We also believe that when non-compliant settings are altered to become permissible, that this is done through a legally enforceable agreement. Furthermore, OPWDD should have an approved process in place for dis-enrolling a setting if it fails to maintain its HCBS-compliant status. There should be consistent quality assurance checks in place to guarantee that these once non-compliant settings do not regress to their previous conditions.

OTHER CONSIDERATIONS

Availability of Affordable and Accessible Housing

New York must increase access to affordable, accessible, and integrated (AAI) housing as part of HCBS implementation in order to ensure real choice to individuals. Lack of access to AAI housing is the number one barrier to people with disabilities who wish to transition from institutions or

other segregated settings or are at risk of institutionalization, who would prefer to live independently in the community. Most people with disabilities live on extremely low, fixed incomes that fall well below 30% of Area Median Income (AMI), making it impossible for New Yorkers with disabilities to afford much of the available housing. In addition, people with disabilities often cannot find housing that allows them to literally get in the front door, for example, if they use a wheelchair.

There are inadequate requirements to build apartments and homes that are accessible to people with mobility and sensory disabilities, and the current requirements are poorly enforced. Compliance with the CMS HCBS rules makes opportunities available for people with disabilities to live in an integrated community-based setting that is not tied to their services.

In order for the disability community to fully realize the benefits of these rules, New York must also address the affordability and accessibility of integrated housing options in the State. AAI housing is not attached to services and allows individuals to choose services and supports available in the community to support fully integrated community life. Failure to comply with these guidelines will ultimately be against HCBS regulations and Olmstead compliance.

Two things New York can do to increase affordable, accessible, and fully integrated housing in the State are: (1) increase the set aside requirement from the mandated five percent of accessible units for people with mobility impairments and two percent for people with sensory impartments to 10 percent and four percent, respectively; and (2) expand Medicaid waiver housing subsidy programs and home modification services.

Information About the Organizations

The New York Association on Independent Living is a statewide membership organization of Independent Living Centers, community-based providers of services, supports, and advocacy that are run by and for New Yorkers with disabilities of all ages. NYAIL is dedicated to removing barriers to the full community integration of all people with disabilities.

The Center for Disability Rights, Inc. is a not-for-profit, community-based advocacy and service organization for people with all types of disabilities. CDR has been advocating for the full community integration of people with disabilities for over two decades through ending the institutional bias inherent in Medicaid.

NYAIL and CDR are working in collaboration, with funding from the New York State Health Foundation to provide technical assistance and training to the State, providers, and health plans to implement the Community First Choice Option.