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Ohio Department of Medicaid
ATTN: HCBS Transition Plan
P.O. Box 182709, 5th Floor
Columbus, Ohio 43218

Re: Disability Rights Ohio's comments in response to "Ohio's Draft Plan to Comply with New Federal Home and Community-Based Services Requirements" dated December 15, 2014

To whom it may concern:

Disability Rights Ohio (DRO) is Ohio's system under federal law to protect and advocate the rights of people with disabilities in the state. Our mission is to advocate for the human, civil and legal rights of people with disabilities throughout Ohio. We envision a society in which people with disabilities are full and equal members; enjoy the rights of and opportunities available to all people; are self-directed; make decisions about where, how and with whom they will live, learn, work and play; have access to needed services and supports; and are free from abuse, neglect, exploitation and discrimination.

DRO is submitting these comments to "Ohio's Draft Plan to Comply with New Federal Home and Community-Based Services Requirements," which was released to the public on December 15, 2014. The federal Centers for Medicare and Medicaid Services ("CMS") has issued new rules for states' 1915(c) home and community-based services ("HCBS") waiver programs ("waiver programs"), defining for the first time "home and community-based settings" eligible for continued federal waiver funding. CMS has required states to create transition plans specifying how they will comply with these new rules and to allow the public to provide input on their proposed plans before they are finalized.

The Americans with Disabilities Act and the Supreme Court's decision in *L.C. v. Olmstead*, 527 U.S. 581 (1999) require Ohio to administer its services and programs for people with disabilities in the most integrated, least restrictive settings appropriate to their individual needs. Medicaid HCBS waiver programs are a tool states can utilize to ensure people with disabilities are served in integrated settings in the community and to fulfill compliance with their legal obligations. Importantly, however, these new CMS rules recognize that even those individuals enrolled in waiver programs can endure segregation from their communities. These new rules and Ohio's transition plan therefore are an excellent opportunity to ensure that individuals enrolled in waiver programs are truly integrated in our communities and are able to live the types of lives they want to live, with needed services as support for their chosen goals.

Ohio's response to these rules is an important part of its strategic response to the requirements of the ADA. *L.C. v. Olmstead* recognizes that segregation of people with disabilities is discrimination. Thousands of people with intellectual and developmental disabilities across Ohio are required to rely on institutional and segregated services because of the lack of community-based choices in Ohio's system. Given this bias in the system, and as it moves forward in *Olmstead* compliance in other areas, it is important that Ohio ensure that HCBS waiver dollars are used as Congress intended: to support community-based services.

Going forward, collaboration amongst stakeholders, including people with disabilities, families, advocacy organizations, providers, policymakers, and county and state agencies, is crucial to creating a system that maximizes integration, choice and opportunities for people with disabilities. Below is Disability Rights Ohio's analysis of Ohio's draft transition plan, which contains both positive and negative aspects.

Ohio's draft transition plan has several positive attributes which should be acknowledged.

Assessment of non-residential settings: Ohio's draft transition plan properly included an assessment of non-residential settings in its waiver programs through the developmental disabilities system ("DD system") and through the system for those with a nursing facility level of care ("NF-LOC").

Institutional bias in work and non-work day programs in the DD system: It also accurately acknowledges that there is a "significant bias toward facility-based supports" in existing adult day waiver services through the DD system, including adult day support and vocational habilitation programs, and that self-reporting for these settings "significantly underrepresents" those which have the qualities of an institution.

Revisions to administrative rules, compliance tool: Ohio recognizes that several administrative rules, including its behavioral support, free choice of provider, and licensure rules, will need to be revised to comply with the new CMS rules. The transition plan also anticipates modifying the compliance tool used during accreditation reviews of county boards of developmental disabilities and compliance reviews of HCBS providers. The draft transition plan further notes that, upon review of residential care facilities licensed by the Ohio Department of Health (ODH), there is a need to create an administrative rule on person-centered planning and community characteristics and to modify provider certification and oversight rules to ensure compliance, which are all positive.

Assessments for some settings are incomplete: The draft transition plan correctly states that, in order to assess completely whether or not settings have the effect of isolating people from the broader community, additional work and information (through on-site evaluations, as an example) will be necessary.

Transitions DD waiver: The decision to discontinue the Transitions DD waiver program and transition people to the Individual Options (IO) waiver since the former does not offer opportunities for integrated employment is a good idea, but will require that the IO waiver is amended to cover sufficient and comprehensive nursing and other necessary services and that the planning instrument (DDP) does not punish those who live at home with their families by placing undue burden on "natural supports."

Diverse means of commenting on draft transition plan: Finally, Ohio has provided many different ways (telephone, meeting, mail, fax, and email) for individuals to comment on its draft transition plan, though smaller, more intimate meetings with stakeholders are preferable so more people have a chance to engage in the discussion.

Ohio's draft transition plan has numerous aspects which are troubling and which should be corrected.

Input from people with disabilities and their families: To evaluate waiver programs administered by the Ohio Department of Developmental Disabilities, Ohio distributed a survey to residential, vocational, and day services providers "to assess their locations to determine level of compliance" with the new CMS rules (county boards of developmental disabilities apparently were also given the ability to assess these same locations, but there is not additional information on this). For the NF-LOC system, Ohio also

significantly relied on provider assessments, although information from the PASSPORT administrative agencies was also utilized.

The input of providers is important (valuable information was obtained regarding common barriers to compliance with the new CMS rules, including “changes to person-centered plans, improved linkage to the community, and staff development and training”) but insufficient. Providers, however, have a particular point of view and can only report from that perspective. This point of view will be biased toward the status quo and, if accepted, would necessarily weaken the impact of the rule. The provider perspective in many cases will be different than the viewpoint of the people who actually receive HCBS services and who are the actual beneficiaries of the program. Ohio’s decision to rely so substantially on provider self-assessments is likely to produce an overstated figure of the number of settings that comply with the new CMS rules.

Ohio should have included input from people with disabilities and their families as the foremost part of its assessment process. This would have presented a much more accurate picture of the characteristics of residential and non-residential settings. Discussions with people with disabilities are essential since they can provide their own accounts of the nature of their experiences as enrollees in waiver programs and identify any obstacles to community integration. Each person with a disability enrolled in a waiver program has a unique and important perspective on whether the setting in which they are receiving services actually is integrated in and supports access to the broader community, provides them opportunities to engage in community life, and allows them independence in making life choices, as is required by the new CMS rules. As the transition plan already correctly acknowledges, “integration is about what the individual experiences, and must be understood as being individual-specific.”

Also, the Transition Plan subcommittee completed reviews of state systems and residential and non-residential settings, but it does not appear people with disabilities or their families participated in this review process. Involvement of people with disabilities through the entire process for ensuring compliance with the new CMS rules is critical. This includes the assessment process for evaluating settings, revising administrative rules, the formation of workgroups, and, most importantly, on-site evaluations of settings subject to the heightened review process.

On-site evaluations: Ohio determined that it would conduct on-site evaluations of only the residential providers who conceded that they should be “presumed to have the qualities of an institution” or which cannot meet the new CMS rules, approximately 1% in the DD system. While these evaluations are necessary, on-site evaluations should be expanded to include a broader sample of residential settings, not just those settings chosen solely because of the provider self-assessments.

Again, the main focus of on-site evaluations absolutely must be the people who are receiving HCBS services and their families. It is axiomatic that any evaluation of the nature of experiences of people with disabilities enrolled in waiver programs should include their own perspectives. Ohio should consider a formal process by which a HCBS recipient can request an on-site evaluation.

Adult day waiver service programs in the developmental disabilities system: Ohio’s preliminary assessment of the adult day waiver service (ADWS) settings (both work and non-work settings) in the developmental disabilities system should have concluded that the vast majority (if not all) of these facility-based settings are settings that isolate people and therefore are presumed to have the qualities of an institution subject to heightened scrutiny. These are settings designed specifically for people with

developmental disabilities and provide little interaction with nondisabled peers (besides staff) and the broader community.

Also, like residential settings in the developmental disabilities system, a sample of on-site evaluations for these day programs should be completed, not simply those small number of settings which providers reported are presumed to have qualities of an institution or which cannot meet the new CMS rules.

Ongoing education: The transition plan should contain a robust process for providing ongoing education, through language and in a format that is easy to understand, for people with disabilities and their families about the new CMS rules, what changes will be made to the system and the timelines involved, the importance of the *Olmstead* decision, and each person's right to live and work and spend their time in the most integrated setting in the community. There have been reports of widespread confusion and misinformation about the new CMS rules. Many people mistakenly believe that services will be instantly terminated or programs will be immediately closed

Ohio should also ensure that these ongoing education efforts are designed to reach people with disabilities and their families; web-based person-centered planning resources, for example, will simply not be effective in a lot of situations.

Overarching administrative rule defining HCBS settings: A proposed new overarching administrative rule specifying the settings in which HCBS may not be provided is incomplete. It should replicate the new CMS rules and also describe the settings and the nature of the individual's experiences which will qualify for HCBS funding. There should also be an enforcement mechanism for waiver enrollees to challenge any setting that is not compliant with this new administrative rule and also additional oversight to ensure compliance. At the same, it should contain guidance to providers on how they can ensure they are complying with the new CMS rules.

Moreover, in a provider-owned or provider-controlled residential setting, the new CMS rules require that additional conditions must be met, including the existence of a legally enforceable lease agreement and protections, the freedom of privacy in the sleeping or living unit but also the right to have visitors, entrance doors lockable by the individual, a choice of roommates for those sharing units, the freedom to furnish and decorate the sleeping or living unit, the freedom to control one's own schedules and activities and to have access to food at any time, and physical accessibility. Modifications to these conditions, according to the new rules, must be supported by a specific assessed need and justified in the individual's person-centered service plan.

Ohio should clarify that an individual has a right to due process upon proposed modifications to these conditions. This must include prior written notice and an opportunity to challenge any proposed modifications with which he or she disagrees.

Timeline: Ohio should not rush its efforts to ensure compliance with the new CMS rules. It must commit to make the changes necessary to ensure true community integration for waiver enrollees throughout the state. More immediate changes that do not achieve full compliance should not be pursued. However, at the same time, Ohio should implement benchmarks and timelines to make sure sufficient progress is being made, and these should be transparent to people with disabilities and the broader public.

Heightened scrutiny process: The new CMS rules require CMS to apply heightened scrutiny if a state wants to use waiver funding for settings that are presumed to have the qualities of an institution, including

[“a]ny setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS... .” CMS will make a determination whether a particular setting has the qualities of home and community-based settings based on information presented by the state or other parties.

As stated above, Ohio’s decision to rely on provider self-assessments to determine which settings will be subject to heightened scrutiny is deeply flawed. Ohio should include people with disabilities and their families as well as advocacy organizations and the general public in identifying settings that should be presumed to have the qualities of an institution and which settings should be subject to the heightened scrutiny process.

Relocation: In situations where it concludes there is insufficient evidence to show a setting is not institutional in nature, Ohio should have included in its draft transition plan a more specific and detailed plan for those individuals for whom relocation is needed. Relocation must include a person’s preferences in accordance with his or her person-centered plan and must occur in a way that is not unnecessarily disruptive to his or her life. It should ensure stability and continuity of services, and no reduction or termination of services should occur during the relocation process.

Increased capacity for scattered-site housing, integrated day services, and transportation: To provide people with disabilities with real choices where they reside and receive the services they need, Ohio needs to ensure adequate capacity of scattered-site housing in the community. This is imperative, especially since the new CMS rules state that an HCBS setting should be one that “is selected by the individual from among settings options, including non-disability specific settings and an option for a private unit in a residential setting.” The draft transition plan failed to discuss this important topic. Ohio must also evaluate its current capacity for non-disability specific, non-residential settings and provide people with real options for working and spending their days in integrated community settings.

It should also work with other state agencies and policymakers to expand access to transportation (public transportation in rural areas is an enormous need, for example). Access to transportation is a crucial way of ensuring meaningful community participation for people with disabilities.

Disunity between the plan for the DD system and the NF-LOC system: Although there are some similarities, the transition planning process appears to be completely separate for these two systems. There should be an overarching transition planning group that has representation from all relevant state agencies and from all populations of people with disabilities enrolled in Ohio’s waiver programs (people with developmental disabilities, people with physical disabilities, people age 60 and older).

Respectfully,



Michael Kirkman
Executive Director