

University of Cincinnati University Center for Excellence in Developmental Disabilities  
Cincinnati Children's Hospital Medical Center

January 22, 2015

Ohio Department of Medicaid  
ATTN: HCBS Transition Plan  
PO Box 182709, 5<sup>th</sup> floor  
Columbus, OH 43218

Re: UC UCEDD'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:

The University of Cincinnati University Center for Excellence in Developmental Disabilities (UC UCEDD) is committed to working with and on the behalf of individuals with disabilities and their families. UC UCEDD envisions a community in which all people, including children and adults living with disabilities, and their families, fully participate in society and live healthy, safe, self-determined, and productive lives. We recognize this goal's connection to your current arduous work on CMS regulations and our organization has paid close attention to these new regulations and the redefinition of Home and Community-Based Services. We would also like to acknowledge our awareness that Ohio must incorporate a number of recent federal changes to HCBS and the process related to these revisions.

UC UCEDD is submitting these comments to "Ohio's Draft Plan to Comply with New Federal Home and Community-Based Services Requirements", which was released for the public on December 15, 2014. Following the plan's release, UC UCEDD appreciated the open, face-to-face forums held by the Department of Developmental Disabilities throughout December and January. Members of our faculty, staff, and community advisory committee were able to participate in some of these forums. While these forums captured the voices of some, it is among our chief concerns that the voices of individuals with disabilities have not been adequately included in this revision process. Ohio, like many other states, has a lengthy history of investing HCBS waiver dollars into segregated settings that have served to isolate the individuals receiving support. Thus, the absence of their voices serves as a function of their institutionalization. It is of the utmost priority to include a more diverse sample of individuals with disabilities at every juncture of this process. There are many opportunities for this inclusion, which we believe would significantly strengthen the plan's effectiveness. Future sources of input should include:

- Disability advocacy organizations, which have extensive experience with a range of settings and individuals' experiences in those settings. These groups of stakeholders are an important source of information for evaluating settings' compliance with the rules and we believe that these groups could also provide access to disadvantaged and institutionalized individuals with disabilities currently underrepresented in the process.
- Consideration for the need for ongoing education. The final transition plan should be written in a more easy to understand and accessible format, including a summary narrative for each

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Waiver. In addition, alternative formats must be provided in braille and/or an audio recording to ensure true engagement of the disability community. The forums have emphasized the existence of problematic and widespread misinformation about the new CMS rules. Even among those offered an opportunity to comment, misunderstanding about basic tenets of the transition is evident.

- The use of smaller, local, more focused meetings of stakeholders at the start and throughout the assessment process. While Ohio offered multiple ways to comment on this draft transition plan (i.e. telephone, meeting, mail, fax, and email), some of these methods exclude large sectors of the disability population. Open forums have exceeded the sensory needs of some individuals and the perspective of a few often overshadows individuals with disabilities who may communicate more effectively in a more intimate setting. Timing of meetings, advance notice, and transportation options must be considered especially carefully to facilitate inclusion of individuals with disabilities.
- Establishment of context. Due to the lengthy history of segregation, many individuals with disabilities, their family members, providers, and other professionals may have few or no examples of successful community living. This challenge to obtaining accurate representation doesn't imply that models don't exist but rather, they may simply not be known to some. To maximize the usefulness of feedback obtained from this most important group-the individuals whose lives will be most directly impacted by these changes-we must first ensure that individuals understand the changes proposed, resolve misconceptions, and provide comments within the context of integrated community living principles.

Ohio must ensure that all ongoing efforts to educate and/or seek comments related to CMS rule changes are designed to reach all stakeholders. We commend the current draft's acknowledgement that "integration is about what the individual experiences, and must be understood as being individual-specific." To achieve this aim, we must work together to better integrate the voices of individuals with disabilities in this process.

As more perspectives are included in the revision process, we are confident that this plan could pave the path to a more inclusive state for Ohioans with disabilities. The timeline of implementation is an important roadmap for these changes. Transparency in benchmarks and progress will allow organizations like ours to best support your work. In addition to assessment of current settings and the tremendous task of updating CMS rules, it will be imperative to prepare provider and community networks for these significant changes ahead. It is our hope that training and education of these very important stakeholders will also be prioritized in the implementation of rule changes.

To offer true choice for people with disabilities in where they live, learn, work, and play, it will also be necessary to increase Ohio's capacity for accessible housing, integrated day services, and transportation options. We are working alongside other state and community organizations to assess the number of residential options available to people with disabilities. UC UCEDD also recognizes the critical need for more and better transportation options for people with disabilities. We facilitate a regional workgroup aimed at researching solutions to this challenge shared by so many across the state and nation.

Increasing capacity in these aspects of community inclusion will be integral in ensuring the long-term success of this plan.

Again, we greatly appreciate the Department's significant work on this draft plan. We recognize the tremendous undertaking in revising these rules to align with federal guidelines while also including the diverse voices of so many perspectives. UC UCEDD would like to offer our connection to research and community stakeholders as a resource to you through this process. We look forward to our shared vision of a more inclusive community and hope to work together to achieve these goals.

Sincerely,



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Ilka Riddle, PhD  
Director



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Kara Ayers, PhD  
Advocacy Coordinator