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February 14, 2018

Dear Mike, Melissa, Ralph and Jodie,

We are writing to follow up on our recent phone call, where our conversation primarily focused on your development of guidance for the heightened scrutiny process. We believe the heightened scrutiny process is a critical part of the HCBS settings rule and that CMS must ensure it is implemented with integrity. A weak or unreliable process could transform a provision meant to accommodate exceptional cases into a vast loophole that stalls national momentum toward improved community integration for people with disabilities. We share some ideas here about aspects of the heightened scrutiny process we see as fundamental to any effective and workable process. As always, we welcome further conversations about these issues.

Consistent with the points discussed in our recent meeting with you, below is a non-exhaustive list of the major components we believe must be part of any heightened scrutiny process:

1. States must have in place **a process that identifies all presumptively institutional settings and ensures that any settings' remediation plans are actually implemented.**
  - As we have previously discussed, we continue to see STPs that do not have a legitimate or transparent process for systematically identifying settings that isolate. Many states describe how they will identify settings co-located with an institutional setting (prongs 1 and 2), but very few are going beyond to identify settings that isolate individuals receiving HCBS from the broader community by their location, characteristics of the setting, operational policies, or relationships with or proximity to other settings. The entire heightened scrutiny process will be undermined if settings that should be closely examined through the heightened scrutiny process are not even identified in the first place. For settings with institutional characteristics states claim can be addressed through remediation, states must have a process (verified by CMS, see below) to monitor and confirm that agreed-upon remediation steps are implemented and that the setting complies with all of the rule's requirements by the end of the transition period.
  
2. As required by the regulation itself, **CMS must have a meaningful and independent review** both of states' processes for identifying presumptively institutional settings and of settings that states submit as overcoming the institutional presumption.
  - The regulation requires CMS itself to determine whether a presumptively institutional setting overcomes the presumption and meets all of the Rule's requirements. We believe that requires CMS to independently evaluate and verify (1) the effectiveness of states' processes for identifying presumptively institutional settings; and (2) that heightened scrutiny evidence packages from states show precisely the institutional characteristics and how the state believes the institutional presumption has been overcome. Regarding evaluating states' processes, we believe CMS must, at a minimum, identify triggers that would require a closer review of settings that were not identified, such as public comments raising concrete concerns about a setting that

should have been, but was not, identified through the process. These triggers should lead to a deeper CMS look behind of the state’s identification process. A similar look behind should be triggered where CMS identifies inconsistencies or errors in a state’s evidentiary packages, such as site review data contradicted by public comments.

We understand CMS has concerns about the potential volume of submitted settings and respect that states desire to control their own process, but this provision of the rule at the least requires that CMS itself evaluate the accuracy and completeness of evidence submitted by the state. Simply accepting a state’s evidentiary package with no independent review would violate both the letter and the spirit of the rule. We have previously provided suggestions on how CMS could manage a heavy review load through strategic sampling (with potential for expansion if systemic errors are uncovered) and would be happy to continue to engage on this process.

3. States must ensure that there is **robust stakeholder engagement** in the heightened scrutiny process, including a transparent and well-publicized notice and comment period.
  - In our last call, DEHPG made it clear that the heightened scrutiny review process will rely heavily on feedback from the public notice-and-comment process. We support public input (in addition to independent CMS review) but recognize that this will not be effective without a transparent and meaningful process. Evidentiary packages must have sufficient detail to allow for meaningful public comment. This includes a clear explanation of why a setting has been flagged for heightened scrutiny, a summary of public comments received about the setting, and a neutral presentation of the measures the setting has put in place that led the State to conclude it has overcome the presumption. CMS must do all it can to not only ensure the required minimum but also encourage active stakeholder outreach by States to publicize their comment process. ACL could play an important role in promoting meaningful stakeholder engagement through its DD network of state DD Councils, Protection and Advocacy organizations, University Centers on Excellence in Disabilities, and ombuds offices.
4. Access to the broader community is a central component to overcoming the institutional presumption for settings that isolate. CMS must require, and state evidentiary packages must include, **information about how individuals actually engage and integrate in the broader community**. Simply documenting “opportunities” for access on paper, as we have seen in some STPs, is not sufficient.
  - Compliance with the HCBS settings rule, including under heightened scrutiny, centers on an individual’s experience in that setting and the degree to which that setting promotes autonomy and access to the community. But promoting access to the community goes beyond posting bus schedules on a community board or providing occasional group trips to the mall. While individuals make different choices about where, how, and how often they interact with the broader community (i.e., people outside of the setting), the degree and frequency that participants actually access the community provides valuable insight on how effectively a setting reduces typical barriers. If a setting provides community opportunities on paper but has few

participants avail themselves of those opportunities on a day-to-day basis, the setting clearly would need to do more to address barriers to community participation (such as staffing or transportation) to overcome a presumption of institutional qualities. For this reason, the heightened scrutiny process must look at both opportunities for community participation and some measure of how participants actually utilize those opportunities.

5. Any guidance on heightened scrutiny should re-emphasize that **heightened scrutiny requirements apply to both residential and non-residential settings.**
  - We recognize that much of the conversation, to date, has focused on residential settings that isolate. But the rule itself makes clear that its requirements apply to *all* settings, both residential and non-residential. As we have discussed numerous times, we think CMS and ACL play a key role in providing technical assistance to states and providers about best practices for complying with the rule in non-residential services. We strongly encourage CMS to reinforce in any future guidance that same general framework for the heightened scrutiny process applies to all settings.

We hope this letter lays out some of our key concerns as you consider next steps on the guidance. We appreciate your ongoing commitment to engage with us and to seek our feedback, along with other key stakeholders, in advance of releasing any further guidance on heightened scrutiny. We look forward to continuing our conversation as you advance your process. If you have any questions, please contact Alison Barkoff ([abarkoff@cpr-us.org](mailto:abarkoff@cpr-us.org)) or David Machledt ([machledt@healthlaw.org](mailto:machledt@healthlaw.org)).

Sincerely,

American Civil Liberties Union  
American Network of Community Options and Resources  
The Arc of the United States  
Association of People Supporting Employment First  
Association of University Centers on Disabilities  
Autistic Self Advocacy Network  
Bazelon Center for Mental Health Law  
Center for Public Representation  
Collaboration to Promote Self-Determination  
Council on Quality and Leadership  
Human Services Research Institute  
Justice in Aging  
National Association of Councils on Developmental Disabilities  
National Consumer Voice for Quality Long Term Care  
National Council on Independent Living  
National Disability Rights Network  
National Down Syndrome Congress  
National Health Law Program  
National Leadership Consortium on Developmental Disabilities  
TASH