



# ADVOCATES FOR AUTISM OF MASSACHUSETTS



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TO: [HCBSWaivers@State.MA.US](mailto:HCBSWaivers@State.MA.US)

I am writing as Chair of Advocates for Autism of Massachusetts (AFAM), a statewide grassroots organization consisting of 13 member organizations, advocating on behalf of individuals on the autism spectrum. We wish to comment on the State Transition Plan for Compliance with the Home and Community Based Services Community Rule July 2016 Revised Draft (**STP**). We have revisited our 2014 discussion and debate of the Department of Development Services' "Home and Community Based Policy 2014-1" (**Policy**), EOHHS summary of comments on the prior public draft of the STP, and the current draft of the **STP**.

The intent of the **Community Rule, Policy and STP** is to maximize opportunities for people receiving HCB services to benefit from community living and receive services in the most integrated setting possible **appropriate to their needs**. The **Community Rule** is a means to an end; it is not an outcome in and of itself. Thus, for any given person, application of the **Community Rule** must be rooted in a person-centered approach. Only this approach complies with the mandate of the *Olmstead* decision; individuals must be allowed to exercise personal choice in how and where they live.

- I. **AFAM wholeheartedly endorses the intent of the Community Rule, Policy and STP. We do, however, have deep concern that the Community Rule and Policy, if rigidly implemented, will jeopardize the health and safety of individuals on the spectrum who live in provider owned or controlled properties.**
- The **Community Rule** and **Policy's** standards for provider owned or controlled properties are not currently designed to take into account the needs of many individuals with autism. The current standards require that bedrooms include entrance doors *lockable by the individual* and that individuals have *freedom to control their own schedules and activities, and access to food at any time*. These are outright dangerous practices for some people!
  - While these standards **may** be modified based on a person's needs and choice, necessity for such modification must be assessed periodically and documented in the Individual Service Plan. According to CMS guidance, documentation must include evidence that less restrictive measures were tried and failed before the modification will be accepted. The guidance does not detail how frequently (every year in advance of the ISP?) such trials must be conducted and how DDS or provider staffs are to evaluate the risks of these trials. The CMS guidance must be more-modification-friendly and modification-flexible

- *Many individuals with autism who currently live in DDS-funded housing have absolutely essential modifications to keep them safe and healthy. (Indeed, their families also live with such modifications to keep them safe when in the family home.) Door and window alarms prevent elopement. Access to household cleaning products, toiletries, medications, small household items and foods are restricted due to pica, allergies, and compulsive over-eating. Such modifications are clinical responses to risky episodes. Reducing injury, trips to the ER, hospitalization, and reducing possible deaths are a constant endeavor with some individuals, and safeguards must be in place.*
- In a system where the default *mandates the absence of all such restrictions*, safeguards must be adopted to ensure that the clinical needs of these individuals are taken very seriously. DDS and provider staff must be trained continuously to be alert to these clinical needs and not be pressured to remove these vital protections during the annual ISP process. After all, just one elopement or ingestion of a cleaning product can result in serious injury or death. Therefore, ISP safeguards must be a constant during any ISP review process.
- Schedules and external prompts also are critical to many with autism to encourage full participation in activities of daily living and community activities, including employment, volunteer activities and recreational opportunities. Many people who are more affected with autism cannot imagine what they could or should be doing in their daily lives, and depend on schedules made by others. Some do not know how to make a choice. Visual and written schedules often decrease these individuals' anxiety and avoid property destruction from meltdowns and other challenging behaviors. These augmentations must be incorporated into any programming and staff training.
- Other modifications are crucial to take into account communication deficits, behavioral needs and need for ongoing structure and predictability that help ease neurologically-based sensory overload that is frequently present with autism, and can lead to outbursts, aggressions and other maladaptive behaviors. Ignoring this creates needless confusion and chaos (and worse) for an individual.
- There is a significant subset of people with autism who have seriously challenging behaviors, even with implementation of Positive Behavior Support models. Sometimes a seizure or medical condition is a contributing factor. DDS Licensed Practical Nurses are often needed to assess or to administer to a situation. These occasions require intensity in staffing numbers to maintain everyone's safety; this is difficult to provide in isolated community-based programs. Sharing of specialized staff - which are proximate enough to be available and be quickly accessible in crises should be facilitated. This is clinically and fiscally responsible.
- Trained behaviorists who know the person should be available in real-time to help when an incident occurs. While it is vital to train Community First responders, and we appreciate the funding DDS has provided in supporting the ALEC program, these Community First responders should not be the only responders available. Their very presence may escalate the situation. It would be naïve to think we do not have to worry about escalations, similar to the one that just occurred in Florida, ever happening again.
- Specialized supports and staffing should not be dismissed as characteristic of institutions; they are the very things that keep some individuals with severe autism safe and out of hospitals and able to be in community settings.

***The Community Rule and Policy should explicitly recognize these realities and call attention to the fact that many such people need to rely on modifications to the Community Rule to ensure their safety, health and well-being and to maximize their participation in the broader community. To do otherwise is to discriminate against these people based on the nature of their autism – with predictable punishing outcomes.***

- II. **The Policy and STP should be amended to permit a range of housing models; this would acknowledge the varied needs of the population on the autism spectrum, while upholding the rights of individuals to live in the community in the way that is most efficacious for them as determined through a person-centered planning process.**
- The **Community Rule** is broad enough to support this vision, *if* the Department of Developmental Services is not too rigid in its interpretation of the guidance provided. The **Community Rule** states, in regard to farmsteads, campuses, and gated communities: *“The Secretary will determine through heightened scrutiny, based on information presented by the state or other parties, whether such complexes do or do not have the qualities of an institution and whether these complexes have or do not have the qualities of home and community-based settings.”* It is premature for DDS to rule out such options in its **Policy**. This is particularly true given that the prototype intentional communities in Mass. – SAGE Crossing, Cape Cod Village, and F.O.R.W.A.R.D. – are all rooted in a vision of participation in the larger community, as well as smaller communities that afford a variety of experiences. This is the way most people without disabilities live—they participate in a variety of communities to meet their needs (church communities, school communities, communities that share something in common with them) and associate freely with different groups of people. Why should this not be permitted for people who are disabled and receive HCB services?
  - In restating the **Community Rule**, the **Policy** employs more restrictive language and drops all reference to the federal heightened scrutiny process (e.g., “farmsteads located in rural areas with little access to the broader community” becomes “farmsteads” on a list of settings that have characteristics of isolating individuals from the broader community). The **Policy** relies instead on a list of prohibited settings (Section E) and a list of settings that will comply (Section F).
  - As the **Community Rule** itself provides, location is not integration. While we understand that the **Community Rule** subjects settings that are not clearly located in the “broader community” to heightened scrutiny, we must point out that, in practice, the administration of community-based services has frequently resulted in services for individuals that re-assume the worst characteristics of institutional care. These characteristics include social isolation and sheer physical isolation (e.g. sitting in one room for hours on end in a subdivision house “in the community”) because of failures to provide reasonable accommodation and necessary supports to meet the needs of many people with autism. (Indeed, it is ironic that EOHHS on pages 41-43 of the **STP** discusses and demonstrates how people on the Frail Elder Waiver who have chosen to live in congregate housing may receive HCB services in those settings because the settings are facilitating community involvement.)
  - The **Policy** provides that an exception to the **Policy** may be granted “only for good cause” (without further explanation) (Section H). The exceptions process is not tied to the heightened scrutiny process described on p. 47 of the **STP**.

- The **STP** states (p. 47) that should the State identify any residential or non-residential settings that are presumed to have the qualities of an institution, but which the State determines through its review are in fact HCBS in nature and therefore in compliance, the State will put such providers/settings forward for heightened scrutiny. The process described in Steps 4-7 of the chart on p.47 should be elaborated upon to provide for reasonable timetables for the process to unfold and further information with respect to documentation required. The exceptions process in the Policy should be amended to conform to the heightened scrutiny process. Heightened scrutiny review should be available in advance of the operation of settings so that creative models that in fact may allow for greater community involvement than the traditional group home can be approved in advance and investment in those models allowed to move forward.

***The language in Sections E, F and H of the Policy should be revised to reflect the heightened scrutiny process of the Community Rule, and the STP should anticipate a number of housing models that can be shown, through heightened scrutiny, to meet the requirements of the Community Rule. Otherwise, Massachusetts may fail to provide the necessary supports some stakeholders need to access the community and may limit the freedom of choice required by a person-centered process, in the name of an unnecessarily blinkered vision of community.***

- III. There is little detail in the STP that is specific to Community Based Day Services. In formulating more specific guidance and policies, CMS and DDS should not assume that all people who receive HCB services during the day can receive those services solely in the community. Many individuals, including many with autism who have severe and moderate needs, are best able to maximize daily opportunities to work, volunteer or recreate in the broader community with service models that incorporate a center to accommodate their needs, including access to nursing and specialized staff, over the course of a day as reflected in their person-centered plans.**
- IV. As the State and DDS moves forward we ask that stakeholder groups that are convened around services to individuals, including individuals on the autism spectrum, always include representative stakeholders from the full spectrum, including the more involved end of the spectrum. These representative stakeholders should include family members who can speak for those individuals who cannot self-advocate due to the nature of their disability, and should include organizations that advocate on their behalf or provide supports and services to them. . AFAM is such an organization. AFAM therefore should be a significant part of the stakeholder group going forward.**

Thank you for this opportunity to include our comments.

Very truly yours,



Michael J. Borr  
AFAM Chairman