



August 10, 2016

Executive Office of Health and Human Services (EOHHS)
One Ashburton Place
Boston, MA 02108

Re: The Massachusetts Statewide Transition Plan for Compliance with the CMS Home and Community-Based Services Community Rule July 2016 Revised Draft

To Whom It May Concern:

Thank you for considering our comments regarding the *Massachusetts Statewide Transition Plan (STP) for Compliance with the CMS Home and Community-Based Services Community Rule July 2016 Revised Draft*. On behalf of the 134 human service providers who offer services for individuals with intellectual and developmental disabilities (I/DD) and acquired brain injuries across the Commonwealth, ADDP submits the following comments to the revised "Community Rule" draft plan for Massachusetts regarding residential and non-residential services and supports.

ADDP strongly stands behind the overall intent of the plan to fully integrate individuals with disabilities into the community alongside persons with and without disabilities. ADDP and its members support inclusion and the reduction of segregation in residential, day, and employment settings, as required by the Centers for Medicare and Medicaid Services' (CMS) Community Final Rule. CMS holds failure to adhere to this definition as grounds for loss of federal reimbursement of Home and Community-Based Services (HCBS) funding. Such loss of federal funding would be catastrophic for the Commonwealth's fiscal condition.

Both the Commonwealth and ADDP have noted that implementation of the HCBS Final Rule on Community Living will require substantive changes to many current supports and services provided by the Massachusetts Department of Developmental Services (DDS), Massachusetts Rehabilitation Commission (MRC), and the Executive Office of Elder Affairs.

The substantive changes needed to occur to meet compliance with federal regulations cannot be implemented on existing fiscal resources. It will require additional investments and increased

appropriations to move people from segregated settings, deemed in violation of the CMS Final Community Rule, to more inclusive settings.

Modifying day, employment, and residential programs to reflect an inclusive outcome requires additional staffing. For example, partial funding that supported closing sheltered workshops has not been sufficient to provide more staff intensive supports and services required to meet HCBS Final Community Rule requirements.

While the Commonwealth's aspirations have been to support the HCBS Final Community Rule, its appropriations to specific line items tied to these services have failed to meet the test of the Final Rule. If not sufficiently funded, it will jeopardize our state's ability to comply with CMS' requirements.

Thus, without assurance of adequate funding for HCBS Community Rule Compliance, ADDP can only offer its endorsement of the aspiration behind Massachusetts' Statewide Plan for Compliance with CMS' HCBS Rule. ADDP will conditionally offer further endorsement contingent upon the assurance by the Commonwealth that the full appropriation for such systemic transition and compliance will be sought and secured.

To provide said assurance, ADDP requests the Baker Administration assure CMS and the public that the following actions will be sought to show the state's intention to honor its commitment to meet the Final Community Rule:

1. Funding of fiscal year 2017 supplemental budget request for \$10 million for line item 5920-2025 to restore the 5% DDS Employment contract reductions.
2. Funding of fiscal year 2017 supplemental budget request for \$4 million for line item 5920-2026 to restore the \$4 million the legislature reduced from the governor's budget for *Blueprint for Success* transition implementation
3. Fund \$30 million in HCBS Compliance in fiscal year 2018 for Residential and Day/Employment budgets and fully fund HCBS Compliance in subsequent years.

Furthermore, ADDP has deep concerns about the provisions of the Massachusetts' STP that will utilize survey and certification procedures and state agency personnel to hold providers accountable for HCBS Final Rule adherence. Respectfully, unless HCBS Final Community Rule Compliance is sufficiently funded by the Commonwealth, ADDP formally requests that I/DD providers be excluded from being held accountable in certification and survey evaluations for Final Community Rule compliance. It is our belief that the entity to be held accountable must be the Commonwealth itself because of its ability to fiscally commit to the CMS Final Community Rule.

Success in this matter will require a collaborative effort between all parties. ADDP intends to work closely with Governor Baker, Executive Office of Health and Human Services (EOHHS), CMS, Massachusetts legislature, Disability Law Center, and others to closely monitor the Commonwealth's adherence to and funding of the CMS Final Community Rule. If it is not adequately funded, ADDP will

seek administrative and legislative remedies to prevent CMS from penalizing the Commonwealth for non-compliance with the Final Community Rule.

Residential

ADDP firmly believes that individuals receiving HCBS services should live in settings that are integrated in and support full access to the community. Community access should provide each person with appropriate opportunities for integrated employment, engagement in community life, control over personal resources, and the same degree of access to community activities and services as individuals not receiving HCBS services.

However, we strongly suggest a change to the Massachusetts State Transition Plan (STP) in regards to access to food at any time for individuals with Prader Willi syndrome (PWS). For all people with PWS access to food at any time is contraindicated.

Individuals with PWS want to eat constantly because they never feel full (hyperphagia), and many health complications of PWS are due to obesity and can lead to death. To compound this problem, people with PWS need less food than their peers without the syndrome because their bodies have less muscle and tend to burn fewer calories. The National Institutes of Health recommends that [caregivers] “should lock refrigerators and all cabinets containing food” (<https://www.nichd.nih.gov/health/topics/prader-willi/conditioninfo/pages/treatments.aspx>).

We appreciate that participants can have modifications made in their individual support plan (ISP) or person-centered service plan, but a person with PWS may not agree to include a food restriction in their support plan. If such a restriction would need to go through the Human Rights Committee or other modification processes, the individual may be at-risk during the time it takes for the modification to be put in place. It is not unusual for a person with PWS to gain 15 pounds in one weekend when given access to food at any time. Because access to food can be life-threatening, it is imperative that access to food be restricted for individuals with PWS, not as a modification but as a health and safety preventative treatment measure. **We recommend that any reference in the STP to “access to food at any time” include a qualifier that will “exempt individuals diagnosed with PWS” as having access to food at any time.**

ADDP would also like to acknowledge DDS for its collaborative efforts assisting residential providers, who needed additional supports to ensure compliance with the Community Rule, to develop transition plans to ensure full compliance with the HCBS Community Rule. ADDP also appreciates that DDS worked with providers to revise the current survey and certification tool to incorporate outcomes contained in the Community Rule.

As referenced above, ADDP asks that residential services be funded at a level that to ensure HCBS Compliance.

Non-Residential

As referenced in the *Blueprint for Success: Employing Individuals with Intellectual Disabilities in Massachusetts (November, 2013)*, ADDP collaborated with the Massachusetts Department of Developmental Services (DDS) and other key stakeholders to develop a plan to transition individuals with I/DD out of sheltered workshop settings into more integrated day and employment services. ADDP is very proud that our sector has closed all sheltered workshops as of June 30, 2016. This means that about 3,000 individuals have left sheltered workshops.

Unfortunately, **most individuals in segregated employment sites or sheltered workshops moved into non-work settings that are not truly integrated in the community**, specifically Community-Based Day Services (CBDS), due to lack of funding for employment programs. CBDS is also not funded at a level that allows increased community inclusion. Currently, out of the 6,143 participants enrolled in CBDS, 2,683 individuals are full-time in CBDS (meaning no employment services or supports) regardless if s/he wants to work or not. This lack of funding violates the intent of the Final Community Rule and has the potential to cause CMS to withhold HCBS federal reimbursement funds.

ADDP appreciates that DDS, during the transition to close sheltered workshops, has worked on the following:

1. Supporting providers by (a) offering various staff development and trainings and technical assistance and consultation and (b) by expanding the employment collaborative model, which conducts macro-level job development, to most catchment areas in the Commonwealth.
2. Redesigning the scope of CBDS, given the flood of participants who quickly moved into CBDS over a short period of time, to weave in career exploration and discovery and soft skills training for individuals with I/DD whose person-centered goal is securing a job. ADDP continues to work with DDS on this issue.
3. Creating assessment standards for community integration of group supported employment. ADDP will soon meet with DDS to begin this work, which will also include further discussions of the use of the sub-minimum wage certificate.

However, **several factors remain that will impede providers (outside of their control) from reaching community integration in non-residential settings** as defined by CMS' Community Rule and in Olmstead:

1. The Commonwealth has not funded day and employment programs in fiscal years 2015 – 2017 at the level that will allow providers to safely integrate individuals in the community. ADDP, DSS, and other stakeholders agreed via the *Blueprint for Success* that in order to successfully transition individuals out of sheltered workshops and alter CBDS and employment services to better meet participant needs and community integration goals, it would take four years and \$26.7 million to accomplish the goal. To date, \$8 million out of \$26.7 million has

been secured for the 5920-2025 budget line item (day/employment). Furthermore, in fiscal year 2017, the day and employment line item was underfunded by \$10.8 million causing a 5% cut in all DDS employment contracts. As a result, the budget shortfall has parked more participants in CBDS who are without the option to work and fully participate in the community, which violates the CMS Community Rule.

2. Since CBDS is shifting to an integrated community-based program and program utilization has dramatically increased since sheltered workshop closure, it has now become more critical to fund this program at an adequate level in order to provide quality community-based programs. CBDS is limited in community integration opportunities given the current staff-to-client ratios. The payment rate for CBDS is based on intensity level (A – G) assigned to participants. DDS has determined that the average staffing ratio in CBDS is 1:3 to 1:4. Therefore, DDS has committed to eliminating *new* clients from entering levels E – G (ratios range from approximately 1:5 to 1:7) because it is not possible given client needs for only one staff member to safety oversee five to seven individuals in the community. DDS has also stated that they would like to move *existing* consumers out of levels E – G and into at least level D, but lack of funding for the *Blueprint for Success* has made it impossible to fully achieve this shift. Rates must reflect costs of providing CBDS in the community to clients who fall in intensity levels A – D to achieve HCBS compliance through smaller group sizes and higher staff-to-client ratios. The rate must also take into account transportation costs, especially for increased inclusive outings. ADDP conducted a study on CBDS with seven agencies in regards to complying with the HCBS requirements of integration that was based on spending at least 50% time in local communities. Results indicated that the rates will need to drastically increase at all intensity levels to meet the Community Rule and to obtain additional resources necessary to operate quality services.
3. The STP states several key policy initiatives that are underway to assist in successful sheltered workshop closure as outlined in *Blueprint for Success*. The goal has been for individuals in sheltered workshops to transition from sheltered workshops to enhanced CBDS and/or individual or group supported employment. Page 11 of the STP references that the goal for group supported employment is for individuals to be paid at or above minimum wage further noting in table 3 that full implementation of the *Blueprint for Success* would be in compliance with the Final Community Rule by March 2019. However, providers, DDS, and other stakeholders agreed during the construction and implementation of the Blueprint that the goal was to increase the number of participants in group supported employment earning at least minimum wage or higher. The Blueprint group conceded that this might not be possible for all participants without a significant infusion of new dollars from the Commonwealth and a drastically improved economic climate. ADDP supports a transitional period to achieving higher wages for all people with disabilities; however, this may not be possible in the time frame set within the STP. Thus, providers may be required to continue utilizing all Department of Labor authorized options for a period of time. ADDP and DDS will soon convene a collaborative workgroup to develop assessment standards for community integration in group supported employment and to continue the discussion of subminimum wage in group supported employment.

While ADDP and its members are optimistic about the future of residential, day, and employment opportunities and experiences for people with disabilities in the Commonwealth, the next two budget cycles are critical pieces in the formula to complying with the Community Rule. Without adequate funding to meet HCBS Community Rule compliance, providers will have difficulty achieving goals of the CMS' Community Rule. The aggressive timeline of compliance has left ADDP concerned given the disappointment felt after the 2017 fiscal budget, as well as the two preceding budgets, as it relates to funding needed to successfully implement the *Blueprint for Success*.

ADDP looks forward to working with its partners to ensure the intent of the Community Rule is met and that additional funding is secured to comply with the rule.

Thanks again for the opportunity to submit comments.

Sincerely,



Gary H. Blumenthal
President/CEO



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