*For people with intellectual and developmental disabilities*

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*Achieve with us.*

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To: Dan Tsai, Assistant Secretary HHS & Medicaid Director
Elizabeth Goodman, Director of Long Term Supports/Services, Medicaid
cc: Marylou Sudders, Secretary, Executive Office of Health and Human Services (HHS)
Fr: Leo Sarkissian
Re: Adult Foster/Family care Regulations in Relation to Mental Conditions
Date: October 20, 2017

This memo is focused on the present eligibility criteria for the Adult Foster/Family Care Program (AFC). The May 2017 release of AFC regulations initially resulted in some confusion statewide despite MassHealth staff's effort to train the field. We appreciate the clarifications and changes that took place after their release. The new regulations resulted in The Arc of Massachusetts (The Arc) making its first in-depth review of the AFC program and regulations. This study resulted in discoveries about the eligibility criteria which merit review and revision by MassHealth. We continue to hear concerns from families and others.

Over the next two months, we plan to share three different memos with you, two of which focus on the AFC program with concrete recommendations. The third will focus upon constituent communications. This is the first memo which is focused on the eligibility regulations themselves, including approval for Level 2 billing by providers.

We fear unintended consequences from policy decisions. The AFC program is a cost-effective service which can keep costs of LTSS lower, even as it places financial demands upon MassHealth. The waiver services are typically more robust, but AFC (and the PCA program) leverage partnership from families and others by the nature of the service. I appreciate the dialogue and hope we can work to improve access as you address the high costs of certain health care services and more restrictive programs.

The memo outline as follows:

1. Introduction to constituency and potential barriers to eligibility to those with “mental conditions”
2. Results of survey from providers/caregivers supporting those with “mental conditions”
3. Potential/actual barriers to access explained (same barriers did exist within the 2007 regulations)
4. Recommendations for eligibility criteria for AFC to remove barriers (potential and actual) to those with mental conditions
5. Recommendation related to the prohibition of related family guardians being AFC caregivers

1. Introduction to constituency and potential barriers to eligibility to those with “mental conditions”

In the AFC regulations, “medical or mental condition” are the two *general* clinical diagnoses which trigger the application of more specific eligibility criteria as noted in 408.416 (all citations forthwith relate to 130 CMR 408.000.)

Our primary constituency, comprised of individuals with autism, Down syndrome, cerebral palsy, Williams syndrome, Prader-Willi, and other intellectual or developmental disabilities, has faced barriers in obtaining family or community supports for decades. The Arc fought for community-based supports, including closure of large institutions. We also have attempted to make the case that if we build upon family and community connections and resources, the public benefits in two ways. First, those with disabilities are allowed to contribute more readily to the common good and secondly, as a rule, the supports are more cost-effective.

We argue that a matrix of supports is most cost-effective for our constituents as it builds upon individual/family resources. For example, Adult Family Care when with related family members maintains someone in the family (or other) home with or without additional resources from the Department of Developmental Services (DDS). Many may need employment or day supports in addition to AFC via DDS or MassHealth. Those with more significant impairments may require additional assistance may receive DDS funding for specific areas not related to AFC (subject to fiscal appropriation in most cases). The total state net cost often totals $15,000 to $80,000 less when compared to intensive shared living or residential costs. The flow of federal reimbursement (match) for state plan services vs. waiver services is another cost factor to keep in mind.

The stigma of exclusion and rejection has always loomed in the background for our constituents. Sometimes the exclusion is unintended. One example of this is in how health care settings fail to accommodate to our constituents’ needs. A partnership study with BU School of Social Work and The Arc documented the lack of knowledge and communication skills among medical professionals in 2008 (published in health journal of NASW in 2011). Other studies have been conducted both before and after including one published by the U.S.

Surgeon General. In the later 2000s, we communicated to the Department of Public Health that their health care disability study didn't adequately survey persons with intellectual disabilities. DPH included an asterisk in their study report to clarify the study's limitations.

We believe unintended bias is the case in regard to how eligibility regulations were developed in 2007 and continue for the AFC program. Those finalizing the regulations were focused on frail elders as opposed to adults with disabilities (although communications at that time demonstrate that our constituents were intended recipients of AFC). Those finalizing the rules/regulations may have felt secure in their crafting given that frail elders may typically present physical limitations along with a decline in mental condition. Moreover, to address the inadequacy of criteria for those with "mental" conditions, MassHealth had softened approval practices over time. The 2017 regulations, the tighter interpretation, communication and impending enforcement reset the barriers to our population. This led to our further review of the specific eligibility criteria.

At the time of those initial meetings, I referenced (and noted in writing) that there appeared to be Olmstead or access implications in the specific eligibility criteria. In addition, communication about changes to providers and constituents was limited. MassHealth did offer to field calls for clarification from providers. But we still experience gaps for constituents with limited information from providers and MassHealth.

Our main concern is that our constituents face barriers to access due to the fact that the regulations are not aligned properly with the clinical diagnosis of the *entire* population that AFC is designed to serve: those with "medical or mental conditions".

2. Results of survey from providers/caregivers supporting those with "mental conditions"

We asked providers and caregivers to fill out a survey to help us understand the nature of the problem with the AFC regulations or eligibility. The survey was completed by 62 individuals who support AFC program members. The people characterized in our survey presented with:

- 37% autism
- 32% intellectual disability
- 16% intellectual disability and physical disability
- 5% autism and physical disability
- 3% physical disability only
- 7% with another developmental disability

The program members were evenly distributed between Level 1 and Level 2 funding and a majority of the members, 76%, receive no DDS funding; furthermore, 81% have no other funding for community living or residential purposes.

Respondents report that AFC is essential:

- 75% of these individuals would reside in a 24/7 group setting or shared living without AFC, so there is personal interruption plus net increased state costs

- Supervision is primary
  - only 30% could be left alone for up to two hours
  - 64% could not be left alone for any period of time

A key issue, perhaps not as obvious, arising out of the survey is very relevant for some of our constituents (as well as for frail elders at the early stages of mental decline). Some individuals may learn skills, but if consistent reinforcement is not available they will lose those skills. This is the tension between habilitation vs. rehabilitation. Although AFC is not required to advance skills, this happens naturally through cueing over time for some of our constituents. These honest respondents worry as they know the individuals will continue needing assistance even if they no longer need bathing assistance. They worry about how their family member or housemate will fare without AFC. The difficulties cited include "his judgement, lack of social understanding, and behaviors". Related to this we found:

- 47% would wander out of the house if left alone
- The same number would also show aggressive behaviors to themselves or others if left alone; also cited were "profound emotional needs and dysregulation."
- Over 70% of the members would show bad judgment and approach strangers, show bad judgment in community travel and be at risk crossing the street
- Half of the members would have no relationships or social contact

An interesting connection to make here is the high cost of those utilizing hospitals, emergency rooms, and psychiatric hospitals. People with disabilities and without social connections do utilize emergency rooms as a form of medical care. High spend should be differentiated by those receiving LTSS and those who do not. Some of the people in this survey would be high spend medical care, which MassHealth is trying to reduce with AFC or other LTSS that keeps them engaged.

3. Potential/actual barriers to access explained (the barriers did exist within the 2007 regulations)

We will connect the issues raised in section 1 and 2 here, but we also point out that MassHealth requires the provider and caregivers to address the "physical, emotional, and developmental needs of the individuals in their care and working in a manner that respects them, their privacy and their property" (408:415 (B) (5) and elsewhere). There is recognition of the range of needs even in program support which is lacking in the eligibility criteria.

As we stated earlier, the AFC regulations note "medical or mental condition," which implies documentation of diagnosis. However, most of the eligibility criteria focus on "physical condition." I reference section 408.416 and 408.419: (D) (2). The latter serves as a payment regulation, but it is an indirect way of defining constituents who may need a Level 2 reimbursement for provider and caregiver. In 408.419 (D) (2), the barrier to access is harsher, as these words define entry -- "hands-on (physical) assistance" -- and there is no reference to

supervision and cueing. I have placed those regulations at the end of this document to avoid the main memo being any longer than necessary.

Consequently, an individual may require 24/7 supervision but in some cases will not be eligible for AFC and more often, ineligible for Level 2 because of the “hands on” requirement trigger. Imagine that the individuals who have 24/7 needs are most likely to cost the Commonwealth an average $150,000 per annum for residential costs (this total would be higher for institutional care). More importantly, the ability to choose is minimized due to a regulation that lacks internal integrity (as defined by coherence).

I use examples to illustrate the problem.

Michael Smith (pseudonym-“psd”) is 31 years old with a diagnosis of autism. He is verbal and appears competent in many ways. He lives at home with a sister. He can be left unsupervised for short periods. As a rule, Michael needs someone to accompany him outside the home. For example, one day without announcement he left the house to visit his mother who lives close by. When no one answered the door, he sat on the stoop, remaining there for 2 hours. Michael requires someone to prepare his food (IADL) but he can eat without prompting. Michael would not purchase or buy nutritious foods on his own. If left to himself he would eat in an unhealthy and irregular manner. His judgment and social judgment are inadequate for independent travel or living. Michael can go weeks without bathing. He needs to be directed and checked once during the bathing period after being assisted with attaining the proper temperatures. Michael would choose summer clothes in winter but would dress in some form (although it’s possible he would sleep in street clothes and use those for several days). He has been Level 1 AFC, but has been at risk of ineligibility.

Janet Guiterez (psd) is 27 and lives with her mother who works full-time. When Janet is not in her day program, mom must work out a schedule with relatives to supervise her. She can never be left alone due to her diagnosis of autism, Down syndrome and pica. She has learned to dress herself and bathes almost independently. She does need help with some female hygiene tasks regularly which allows her to meet the one ADL requirement. She may occasionally have physical assistance needs, but as a rule most of her support is cueing and supervision. Janet’s medical and mental condition should qualify her for Level 2 AFC but the current regulations do not allow it.

George Humphreys (psd) is 42 years old and he has a diagnosis of Schizophrenia. He has received AFC at Level 1 and he intermittently qualifies for Level 2 when his condition is so severe that he requires physical assistance in two areas of ADL. His mental condition is always challenging as he hears voices and sees hallucinations recurrently on a weekly basis. His mood is depressed, reflecting lethargy in his daily routine.

These case examples reflect individuals my colleagues or I have known over the past two decades. The Arc posits that the AFC eligibility regulations need to change to address unintended bias.

4. Recommendations for eligibility criteria for AFC to remove barriers (potential and actual) to those with mental conditions which have existed since 2007.

The Arc posits that the AFC regulations need to:
- Utilize IADLs (Instrumental Activities of Daily Living)
- Remove "physical assistance" as a barrier to Level 2 eligibility
- Prioritize some of the items in 408:419 that are listed as "management of behaviors that require frequent caregiver intervention"

I. Recommendations for changes included for Section **408.416**:

Clinical Eligibility Criteria for AFC
A member must meet the following clinical eligibility criteria for receipt of AFC. Criteria in either B (existing regulations) *OR C (#C recommended) must be met along with the remaining criteria.*

(C) In addition to a formal diagnosis of a medical or mental condition, the member needs cueing and supervision to successfully complete two (2) of the following IADLs:

(1) Household management tasks: Budgeting; scheduling of appointments, bill dates, and activities; paying bills fully and on-time; security of dwelling; negotiating unforeseen problems (i.e. plumbing issues); negotiating changes in dwelling (forced, financial, etc.)
(2)Housekeeping: Laundry; sweeping/vacuuming; dusting; picking up after oneself
(3)Meal preparation and cleanup: planning, purchasing, and preparing meals; operating cooking devices; putting away ingredients; identifying spoiled foods; cleaning dishes
(4)Medical need management: care and maintenance of wheelchairs and adaptive devices; medication management and any paperwork required for receiving prescribed medications; other medical needs instrumental to health care and general well-being
(5) Transportation: arranging for transportation; coordinating public transportation; negotiating changes in transportation routine (i.e. traffic, missed bus/metro)

II. Recommendation for section **408.419: (D) (2):**

(2) Level 2 Service Payment. The MassHealth agency will pay the Level 2 service payment rate for members who require (a), (b) *or (c) (proposed addition)*

(c)The member cannot be left alone for more than 2 hours at a time and shows one of the following behaviors more than once weekly:

(1) Wandering (moving around oblivious to needs or safety) and if left alone may exit the setting without adequate attention to his/her safety;
(2) Verbal or physically abusive behavioral symptoms such as threatening, screaming, hitting, eating objects such as paper, etc.);
(3) Socially inappropriate or disruptive behavioral symptoms: disruptive sounds, noisiness, screaming, self-abusive acts, disrobing in public, smearing or throwing food or feces, rummaging, repetitive behavior, or causing general disruption; or,
(4) Resisting care.

5. Recommendation related to the prohibition of related family guardians being AFC caregivers

When the 2007 AFC regulations were released, a prohibition remained for guardians to also serve as caregivers in AFC. This has proved a significant barrier for:

- single parents
- parents who are aging and have given guardianship to another child but that sole child is planned to become future caregiver
- brothers and sisters who must take on guardianship and are the caregiver due to loss of another sibling or extended family member

We haven't researched CMS regulations on this matter and that is pending.

# ***Appendix of AFC Regulations***

## 408.416

Clinical Eligibility Criteria for AFC
A member must meet the following clinical eligibility criteria for receipt of AFC.

(A) AFC must be ordered by the member's PCP.

(B) The member has a medical or mental condition that requires daily hands-on (physical) assistance or cueing and supervision throughout* the entire activity in order for the member to successfully complete at least one of the following activities:

(1) Bathing - a full-body bath or shower or a sponge (partial) bath that may include washing and drying of face, chest, axillae (underarms), arms, hands, abdomen, back and peri-area plus personal hygiene that may include the following: combing or brushing of hair, oral care (including denture care and brushing of teeth), shaving, and, when applicable, applying make- up;
(2) Dressing - upper and lower body, including street clothes and undergarments, but not solely help with shoes, socks, buttons, snaps, or zippers;
(3) Toileting - member is incontinent (bladder or bowel) or requires assistance or routine catheter or colostomy care;
(4) Transferring - member must be assisted or lifted to another position;
(5) Mobility (ambulation) - member must be physically steadied, assisted, or guided during ambulation, or is unable to self-propel a wheelchair appropriately without the assistance of another person; and
(6) Eating - if the member requires constant supervision and cueing during the entire meal, or physical assistance with a portion or all of the meal.

**2007 "during" not "throughout"*

## 408.419: (D) (2)

(2) Level II Service Payment. The MassHealth agency will pay the level II service payment rate for members who require

(a) hands-on (physical) assistance with at least three of the activities described in 130 CMR 408.416; or
(b) hands-on (physical) assistance with at least two of the activities described in 130 CMR 408.416 and management of behaviors that require frequent caregiver intervention as described in 130 CMR 408.419(D)(2)(b)1. through 5.:

1. Wandering: moving with no rational purpose, seemingly oblivious to needs or safety;
2. verbally abusive behavioral symptoms: threatening, screaming, or cursing at others;
3. physically abusive behavioral symptoms: hitting, shoving, or scratching;
4. socially inappropriate or disruptive behavioral symptoms: disruptive sounds, noisiness, screaming, self-abusive acts, disrobing in public, smearing or throwing food or feces, rummaging, repetitive behavior, or causing general disruption; or
5. Resisting care.