



# ADVOCATES FOR AUTISM OF MASSACHUSETTS



August 23, 2016

Department of Developmental Services  
Executive Office of Health and Human Services  
500 Harrison Avenue  
Boston, MA 02118

**ATTN: 115 CMR 5.00 et seq.: Standards to Promote Dignity**

To whom it may concern:

These comments are submitted by Advocates for Autism of Massachusetts (AFAM), a state-wide public advocacy organization consisting of 13 member organizations, whose mission is to assure the human and civil rights of individuals of all ages across the entire Autism Spectrum and promote the availability of essential supports so that individuals with Autism may live fully and enjoy the same opportunities as other citizens of the Commonwealth of Massachusetts.

We strongly support the Department of Developmental Services' objective of adopting rules that promote the safety, well-being, and dignity of individuals with developmental disabilities. We are grateful for the efforts of the Department to promote the independence, inclusion, and dignity of individuals with Autism through rules and policies that incorporate Positive Behavioral Supports. We have some concerns, however, with specific elements of the rules the Department has proposed in order to implement these policies. The concerns detailed in this letter do not in any way minimize our opposition to any approach or therapy that is painful, that punishes individuals with disabilities, or that includes inhumane practices, such as depriving mealtime food, medicine, sleep, freedom of movement, or self-determination.

Our primary concern relates to the "one size fits all" approach of the proposed regulations, given the wide-ranging needs of the affected population. We are also concerned that there are instances in which the proposed regulations fail to cross-reference the existing regulations with scientifically validated best practices and in so doing may not fully reflect the complexity of provider's legal requirements. In addition, we are concerned that while DDS is including more requirements for providers, the proposed regulations fall short with respect to ensuring provider accountability to affected individuals and their guardians. Our specific comments are outlined below.

## **General concerns about a “one size fits all” approach with regard to behavior management**

AFAM is concerned about the “one size fits all” approach to the regulations. We are particularly concerned about “one-size-fits-all” requirements insofar as they may unduly hamper provider’s ability to maintain the safety and welfare of individuals with highly challenging behaviors. There is a significant subset of people with autism who have seriously challenging behaviors, notwithstanding the implementation of Positive Behavior Supports. These behaviors can be more challenging when the individual is non-verbal or has developmental limitations that restrain the capacity to engage in calming discussions. The risk of self-harm and or harm to others increases when caretakers are not allowed to provide appropriate guidance and fewer tools to support appropriate behaviors and remove protective tools in highly dangerous situations. Additionally, some individuals have had behavioral plans prior to their adult placements that have proven successful when less restrictive interventions have been insufficient to modify unsafe behavior. Discontinuing such proven plans could re-introduce unnecessary risks to the individual’s safety and well-being.

There will be certain individuals served under these regulations, especially those who have a history of self-injurious or very aggressive behavior, for whom there needs to be a protective physical restraint procedure in place to provide a safe alternative during a crisis. Without this option, we are concerned that many adults with the most intense behavioral needs will be shut out of programs, as providers will say they are unable to serve them safely, and ensure their staff are not exposed to unnecessary risks. If a program is willing to serve the individual, and an individual with self-injurious or very aggressive behavior engages in dangerous behavioral episode, it is preferable that the program’s staff be appropriately licensed as a behavior analyst, prepared and trained to handle the dangerous situation.

We acknowledge that supine or other physical holds must be carefully monitored. However, rather than broadly limiting the ability of staff to perform supine or other planned physical holds, we hope that the Department will require a careful process that permits such restraints to be used, subject to pre-agreed and well-enforced guidelines. It is imperative that the rules require comprehensive behavioral plans, more comprehensive ISP reviews than are currently customary, higher credentialing of staff, better staff training, stricter restraint reporting requirements to guardians, and more accountability from providers when there are complaints of abuse and mistreatment during restraints. When it is assumed that a restraint will never occur, the necessary planning and training for such an event is likely to be neglected; this means that when a crisis requiring physical restraint does occur, as it inevitably will for some individuals, the resulting restraint will be performed by untrained staff and is more likely to result in injury to the DDS client and his/her caregiver. For this reason we strongly support Rule 5.14 consent, training, and reporting requirements.

We are concerned about Rule 5.14(4)(b)(9) regarding the use of time out rooms. We support DDS’s commitment to ensuring client dignity and safety in the time out environment and limiting the use of time outs to situations in which the individual poses an imminent danger to himself or others. We are concerned, however, that under the proposed rule the determination as to whether a time out room is safe and fit for the purposes of time out is left exclusively to the head of a facility or program. We recommend that DDS provide oversight of the room conditions as part of a regular facility inspection or program review, rather than ceding this prerogative to an individual who has a vested interest and thus is not impartial.

Rule 5.14(4)(b)(9)(c) should be modified to specifically state that a time out room must be well lit, clean, well ventilated and safe. In this regard, it is not clear that the requirement to keep the time out room unlocked will improve safety under all circumstances (for example, if the person leaves the time out area in order to initiate an aggression). We suggest that you instead require some form of safety-glass window (with minimum dimensions) that would allow those caring for the individual to monitor the well-being of a person inside, and for the individual to be able to see outside.

Finally, we urge DDS to make changes to the proposed rule with respect to the permissible uses of contingent and differential reinforcement. Individuals with autism often require this evidence-based method of reinforcement to learn to discriminate between behaviors that are socially appropriate or not, or that are safe vs. dangerous. We understand that the regulations propose that the use of such methods be preapproved through an ISP and the program's Human Rights Committee. However, we are concerned that DDS clients will be the ones harmed should a provider fail to write a well thought out, carefully designed, and comprehensive ISP that includes differential reinforcement. The regulations should hold providers accountable for ensuring that the ISP meets the needs of the client with regard to behavioral approaches that must be pre-authorized as a part of the ISP process. The provider should ensure the appropriately credentialed clinicians and trained direct care staff.

### **Ambiguous language in certain proposed rules**

Key language in the regulations to limit restraints (both in a facility and during transportation), medications, the use of locks, and guide self-determination principles is too broad and could be misinterpreted by providers to limit the rights of the individuals served. We recommend that the regulations include more specific language to help clarify which approaches are permissible in various situations. In all situations these issues must be brought back to the ISP process and what is appropriate given the individual's needs.

Take for example, the proposed regulation on door locks, which could be either over- or under-inclusive, depending on the circumstances. In 5.11(3) the regulation explains that "[t]he locking of exits from buildings is prohibited, except for the safety of the occupants..." It is not clear from this language what is meant by "the safety of occupants"; thus, a provider could lock an exit against an occupant's wishes, claiming that the action provided security against intruders, when the actual intention and effect was to limit the occupant's freedom. On the other hand, there are circumstances under which the elimination of locks could create an undue risk for individuals who would be unsafe should they manage to elope (an action that may not be fully predictable based on their past behavior).

Similarly, 5.03(e) (General Principles) specifies that services and supports need to provide the "opportunity to undergo typical developmental experiences..." and (f)(5) "[r]ecreation and leisure time activities to the individual's age and the practices of the surrounding community..." While the individual should certainly have the opportunity to select age appropriate leisure time activities, they should also have the option to select preferred and reinforcing activities that may not be, strictly speaking, age appropriate. It is not unusual in the autism population for individuals to retain a strong interest in activities that other their age might have outgrown. These preferences deserve the same respect as those which might be selected by someone with typical development.

Section 5.04(3)(b) establishes that "reasonable restrictions may be placed on the time and place of the visit" to a DDS client. The regulation does not define what "reasonable" means, and this ambiguity leaves room for misuse by providers who may block access to guardians, parents, and friends. We recommend clarification or further guidance with respect to this provision.

## **Cultural and linguistic rights of individuals need to be considered**

The proposed regulations do not adequately take into account the culture, language, and communication preferences of the individuals served by DDS. Massachusetts is home to the 8th largest population of limited English proficient (LEP) persons in the United States, with approximately 550,000 residents (nearly 9 percent of the population) speaking English “less than very well.” Federal regulations define a limited English proficient person as an individual whose first language is not English and may have some level of difficulty reading, writing, speaking or understanding English. We strongly recommend that the regulations address the cultural and linguistic preferences of the individual, rather than just “the practices of the surrounding community” (see 5.03(f)).

Under federal and state law the recipient or sub-recipient of federal and state funds (directly or indirectly) must provide language access in the form of oral interpretation for any individual who identifies as limited English proficient or his/her guardian. Proposed Section 5.04(1) should be modified to require the provider to ensure that there are staff members can understand the language of the individual being served.

Section 5.04(1) does not take into consideration that many persons served under DDS funding have limited speech or communicative abilities. These individuals may not use the telephone as their primary mode of communication. For this reason, we recommend that the rules be expanded to reflect the need of these individuals to communicate with guardians, family, and friends using a variety of communication methods. Broadband Internet access (including robust Wi-Fi coverage), with enough capacity to allow text or videoconference, such as “face time” should be required as part of 5.04(1), so that non-verbal individuals who need to text, video, or use ASL can communicate confidentially with others outside their placement.

Section 5.08 requires informed consent by the individual and/or the guardian. The regulation should specifically acknowledge that individuals or their guardians have the right to receive all vital notices that require consent in their language of preference and that any document that requires the consent of a LEP client or his/her guardian must be translated into the preferred language. Similarly, section 5.08(3)(e), which requires the person securing consent to explain the intended outcome and risks and provide alternatives, should include the requirement that the person seeking consent have a qualified and impartial interpreter present to ensure the LEP client or his/her guardian fully understand the conversation. We strongly recommend the regulations spell out these requirements to ensure the safety of all individuals served by DDS.

## **Mistreatment**

Section 5.05(1)(a) prohibits mistreatment by persons employed in the care of a DDS client. It states “[c]orporal punishment or any other unreasonable use or degree of force or threat of force not necessary to protect the individual or another person from bodily harm” [emphasis added]. We ask that you provide further guidelines in what DDS considers “unreasonable.” Without specific limits or guidelines, it is difficult for providers to train staff, and guardians and the individuals served do not have a specific standard to reference when seeking accountability for the unreasonable actions by the employee of a provider.

As explained in a previous section, we ask that the restricted use of physical restraint noted in section 5.05 be clarified. It currently states under 5.05 that restraints cannot be done “for punishment or the convenience or staff.” However, in section 5.11(4)(b), it would be allowed “after a determination

based upon professional judgment that such [least restrictive] alternatives would be ineffective under the circumstances.” We are not certain who would have the “professional judgment” to make the determination, or what should happen should a provider and a guardian’s privately paid expert disagree on the effectiveness of a less-restrictive intervention.

## **ISPs and Interventions**

The proposed regulations depend heavily on the ISP for authorization of any behavioral intervention that falls outside the rubric of PBS. The underlying assumption appears to be that the process for developing an ISP is comparable to the detailed IEP development process used by school districts for special education services. Reports by parents and guardians suggest that such is not the case, with ISP meetings typically being much shorter and less comprehensive than those for IEPs. In order for the proposed regulations to work as intended, there must be an enforceable expectation that ISP development process, including ISP meetings, will provide the venue, expertise, staff, and time to facilitate an in-depth discussion of all requirements, leading to the creation of written behavioral, restraint, and reinforcement plans that are comprehensive and complete.

Because the proposed regulations prohibit behavioral interventions not discussed in the ISP meeting, it is critical that the regulations mandate that providers take responsibility for ensuring that all interventions requiring specific authorization are addressed as part of a standard ISP meeting agenda. If a guardian or individual is unaware of the new regulations, he or she might neglect to advocate for measures that require specific authorization to override the default requirements of the regulations. For example, a guardian or individual who is not aware of these new regulations may wrongly assume that the provider is permitted to implement a restraint during transportation, have a differential reinforcement system, or lock the door of a room during a strong behavioral outburst, without explicit authorization through the ISP. We ask, therefore, that the regulations mandate that providers cover as part of ISP agenda items any service or intervention that would be allowed only if it is included as part of an ISP, so that guardians or individuals are ensured the opportunity to understand why a treatment is or is not being included as part of the proposed ISP and to provide informed and constructive feedback.

In addition, there is the concern that the proposed regulations over-rely on the use of the rubric of PBS – another instance of a one-size-fits-all approach that will disserve many individuals with autism. The assumption that the current PBS training allows enough support for our most vulnerable individuals is unrealistic. Autism Spectrum Disorders is exactly that, a spectrum, and no one methodology will fully support the whole spectrum. Without the highly trained clinicians, many of these individuals will be unable to live an independent life that promotes dignity in the community. Using PBS does not mean the exclusion of other highly effective clinical methodologies. PBS is primarily a widely accepted cultural values structure; however, without embedding an effective clinical infrastructure for our most vulnerable individuals, it is ineffective.

## **Reporting and Accountability**

We applaud DDS’s attempt to ensure accountability of providers by creating reporting responsibilities, especially in the areas of restraints, medications, and reinforcements. We recommend, however, that these reporting provisions be paired with specific accountability measures. In some instances, this could be accomplished by cross-referencing accountability measures in existing regulations, including those that concern the rights of individuals served by DDS (or their guardians) if any of these rules

are broken. The effectiveness of DDS' new requirements with respect to restraints, medications, and behavioral plans could be undermined if it does not also specify the manner in which an affected individual or his family can seek recourse against a provider that violates these rules. We ask that you include a section in the rules providing for accountability of providers who violate their responsibilities; it is important to also include a provision that specifically prohibits retaliation by the provider against an individual or guardian who invokes these accountability provisions.

We are grateful for the important protections DDS has proposed and the opportunity to comment on how they could be strengthened. As a coalition of 13 organizations that serve the Massachusetts autism community, AFAM has a well-developed understanding of the need for regulations that permit high-quality services to be tailored to meet the needs of individual clients. We would be honored to be included in any subsequent process undertaken by DDS for purposes of refining the proposed regulations.

Very truly yours,

A handwritten signature in dark ink, appearing to read "Michael Borr", written in a cursive style.

Michael J. Borr  
AFAM Chairman