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INDEPENDENT REGULATORY REVIEW COMMISSION

"Restraint is not treatment; restraint is the failure of treatment."
Slogan of the national movement to prevent restraint

July 24, 2007

Mr. Jim Buckheit
Executive Director
State Board of Education
333 Market Street
Harrisburg, PA 17126-0333

Dear Mr. Buckheit:

Pennsylvania TASH appreciates this opportunity to comment on the proposed changes to 22 PA Code Chapter 14. We represent the state chapter of a 32-year old national organization dedicated to researching and advocating for positive approaches to the support of individuals with the most severe disabilities. Our organization has been closely involved with the development of state regulations impacting teacher training, with the current *Gaskin* Settlement, and with the state's special education regulations and practices as they have evolved.

We are writing specifically to address an area of great concern to TASH: the protection of vulnerable children from the use of dangerous restraint. The reasons why restraint is ineffective and counterproductive as behavior management are well known and well documented: restraint cannot teach alternative, adaptive behaviors; restraint *does* teach that might makes right and that physical means of problem-solving are acceptable; restraint destroys the trusting relationship between an individual and his/her teachers or staff which is essential to learning and progress; the stress and anxiety caused by restraint use make it increasingly difficult for a child to respond flexibly, pay attention, and process new information; the effects of restraint generalize to unwanted domains (e.g. a child restrained in the classroom may come to fear and avoid not only the so-called "target behavior" but the classroom itself, the teacher, the school, and the learning process in general); restraint can cause injury, psychological trauma, and even death.

For many years PA TASH has pointed with pride to the protections against restraint that Pennsylvania afforded students in special education, just as we were proud when our state's mental health system became the standard-bearer for the nation in the systemic reduction (and, in some facilities, elimination) of restraint use on patients, and heartened when in 2000 Congress ordered CMS to set a similarly high standard of protection for all children in mental health programs. Now, however, it appears that Pennsylvania's special education system is poised to take a giant step backwards. We would like to draw six main problems to your attention.

1. The proposed changes in PA Code would encourage and increase restraint use. Under current PA Code, when a student exhibits an infrequent and therefore unanticipated dangerous behavior that results in emergency restraint use, parents must be notified and an IEP team meeting convened. This meeting can then be used to find ways of preventing a recurrence of the behavior and the restraint by employing research-based strategies provided for under IDEA, notably the Functional Behavior Assessment, to create an effective Positive Behavior Support plan. Current regulations reasonably assure that, should an unanticipated emergency occur, plans can be made to avoid any future occurrence. They assure that high-risk responses on the part of school personnel will be scrutinized so that they do not become the norm for any student. *Unfortunately, the proposed changes to Chapter 14 would serve to condone and even encourage repeated restraint use far in excess of any occasional emergency response. They would do so by creating two dangerously loose sets of conditions under which restraint can become a routine part of a special education student's school experience: when each individual restraint lasts no more than 30 seconds (regardless of the number of restraints, cumulative time spent in restraint, or reason for restraint), and when restraint use is written into a student's IEP as a planned "behavior support."*

Here is how these two changes in PA Code would create dangerous incentives for increased restraint use:

1. The unprecedented creation of free and unlimited 30-second restraint: School staff would be permitted to utilize the same potentially dangerous restraint techniques that previously triggered new IEP meetings and reporting requirements, and to do so on a virtually unlimited basis without notification of parents, without triggering an IEP meeting, without safeguards and monitoring, and without data collection or reporting requirements, *provided that these techniques are implemented in increments of not more than 30 seconds per hold. When restraint is used in this manner, the proposed regulations would also eliminate the requirement that its use be limited to emergencies. Restraint would be permitted as a response to any behavior school staff dislike, find inconvenient, or wish to punish. A strong incentive for increased restraint use would be created, since disclosure and scrutiny of such usage would be bypassed.*

2. The sanctioning of decreased staff/school consequences for increased student "emergencies": The proposed regulations provide that when there is "evidence to suggest that the emergency use of restrictive procedures, such as restraints, may be necessary" parental consent should be obtained and "if a restrictive procedure is used on an emergency basis" then consent should be obtained and permission for future use should be placed in the student's IEP. *Once restraint use is placed into the IEP, the proposed regulations would no longer require that an IEP meeting be convened whenever restraint has been used, thereby eliminating this important opportunity for scrutiny and for the implementation of positive preventive measures. These regulations would also create a strong incentive for schools to seek evidence of a "need" for restraint, and would reward schools for program failures that result in the use of emergency restraint on a student by lessening the consequences to staff (i.e. reporting, meetings, paperwork) of subsequent restraint use on that student.* Carrying out the restraint of a student with disabilities would become, not a cause for deep concern and careful implementation of improved behavior supports, but the gateway to demands for parental permission for an IEP that condones the ongoing use of dangerous restraint on a vulnerable child. Rather than recognizing a "planned emergency" as an oxymoron, school staff would be encouraged to "plan" to make the same dangerous response to the same foreseeable situation over and over again. Rather than being supported to implement *pro*active strategies that will change, replace, redirect, or de-escalate behavior, school staff would be encouraged to "plan" via the IEP to routinely *re*act via restraint.

2. Placing restraint in an education or behavior support plan creates a false sense of safety.

Consensus has been reached among the national disabilities organizations that restraint does not belong in a child's IEP or behavior support plan (www.aprais.org). Placing it in a student's plan changes the restraint from an infrequent emergency response to a routine and accepted method of behavior management. It says to school personnel that this "approved" restraint is safe and effective for use on this particular student. However, enhanced medical understanding of the adverse effects of restraint even on apparently healthy individuals has left no doubt that this practice can never be considered safe and controllable. Apart from the obvious dangers associated with physical force, awareness has grown of the unpredictable cascades of physiological effects associated with states of high emotional arousal, the dangers posed by hidden medical conditions, and the potentially adverse effects of medications during the application of restraint procedures.

Health care experts have become increasingly aware of the onset and symptomology of psychological trauma, including Post Traumatic Stress Disorder, among individuals with disabilities who have been subjected to restraint. Research has demonstrated that repeated exposure to threatening experiences can interrupt and permanently alter children's brain development, creating repetitive, impulsive activity patterns and an inability to attend to and learn from new information.

Documentation of these health and safety risks prompted Congress to pass The Children's Health Act of 2000, banning the non-emergency use of restraint in CMS-funded programs for children. *If children in psychiatric and other health care facilities cannot be subjected to the types of restraint use being proposed in Pennsylvania's school regulations, why would our schools feel a need to create a double standard? Why would school personnel wish to more freely implement, in the absence of medical oversight, interventions with such serious medical consequences that they are far more strictly regulated within medical settings?*

3. The dangers of prone restraint preclude even emergency use.
In the March 2007 draft of 22 PA Code 14.133(e), prone restraint was included on a list of "aversive techniques of handling behavior [which] are considered inappropriate and may not be used by agencies in educational programs." The current draft reverses course to permit them when "determined by a physician and documented in the student's current IEP." This is contrary to the overwhelming nationwide direction against the use of prone restraint in any circumstances and for any reason. Restraint researchers Mohr, Petti, and Mohr report that positional asphyxia due to prone restraint is the most common cause of restraint-related death, and occurs even when staff are trained and the prone restraint is "properly applied" (http://www.charlydmiller.com/LIB03/2003adverseeffects.pdf). The National Disability Rights Network (NDRN, formerly P&A) warns against prone restraint; the California DRN, in its 2002 report "The Lethal Hazards of Prone Restraint" advises that "Individuals must never be placed in the prone position when restrained." (http://www.advocacycenter.org/documents/The_Lethal_Hazard_of_Prone_Restraint.pdf) The respected restraint training organization MandtTraining, Inc. – the only such organization to submit its practices to medical review – has announced that it will no longer include prone restraint in its trainings and discourages its use under all circumstances due to its particularly lethal record. Three Pennsylvania youth are known to have died due to prone restraint in the past three years, and many others have been seriously injured. The School Code should make it clear that this restraint method is never appropriate or safe.

4. PA Code should follow IDEA in emphasizing "<u>Positive</u> Behavior Support"
The IDEA creates a presumption in favor of Positive Behavior Support. It would be helpful if PA Code followed suit by inserting the word "Positive" before each usage of the term "Behavior Support." School staff should always be reminded that, after more than 25 years of empirically validated research, we have positive and non-restraint-based alternatives for addressing even the most serious behavior problems across the spectrum of diagnoses and severity of challenges. This evidence includes peer-reviewed studies of severe problem behaviors such as self-injury, aggression, property destruction, and severe noncompliance. These positive interventions have been applied in a variety of everyday environments, including public schools, home and community settings, job sites, and typically stressful settings such as a dentist's office. The principle of "least restrictive

alternative" in ethical and legal decision-making holds that when less dangerous or harmful means are available, they should always take precedence.

5. Demands for parental consent to placing restraint in an IEP create insurmountable legal and ethical dilemmas.

The process of obtaining parental permission for the planned use of restraint is highly problematic and fraught with inequities. The common denominator when parents consent to negative interventions is a *lack of real choices*. Parents are not asked "Would you prefer to have your child restrained and immobilized for purposes of 'behavior support,' *or* would you rather that we investigate environmental modifications to prevent sensory overload; adjust your child's schedule, instruction techniques, activities and routines to improve his/her quality of life; develop a reliable system with which your child can communicate; teach your child to initiate rewarding social interactions; expand his/her social play skills; and teach self-organizational skills, new coping strategies, and replacement skills?" They are told instead that it is either restraint or a quick exit from the school or program. This absence of positive choice, in an education system rich in resources – from scientifically researched special education methods to neurologically-based habilitation techniques -- is abusive of parents because it forces them to make choices with which they are profoundly uncomfortable and deeply dissatisfied.

Parents in other states have testified that the desire of schools and programs to place restraint use into students' IEPs inevitably results in the bullying of parents (to gain their consent) and the blaming of parents (for giving their consent) when restraint leads to harm. Some parents are forced to sign a blanket consent for restraint as a condition of their son or daughter's admission to a program. Others report that they gave a coerced consent under the threat that their son or daughter would be summarily expelled. Still others report that confusing language was used to gain their consent; for example, they may have signed permission to use "restrictive procedures" under the misapprehension that the term referred to innocuous precautions such as seat belts on the school bus. In none of these cases has the legal standard of "informed consent" been reached, since the nature and proven risks (i.e. injury, psychological trauma, death) of restraint are not fully disclosed to parents. *Under the proposed changes in PA Code, how will a school "require" parents to give permission for putting restraint use in their child's IEP? What will schools be required to disclose about the risks of restraint? How will a school respond when parents refuse consent? What are the legal and ethical implications for school districts when students are injured or die as a result of the routine use of techniques that are known to be dangerous and that were placed in a child's education and behavior support plan against parental wishes or without reaching the legal standard of "informed consent"?*