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Autism Society of America

– Pennsylvania Chapter –

Comments and Recommendations

July 18, 2007

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INDEPENDENT PEGULATORY

To: the Pennsylvania Board of Education and the IRRC

re: input regarding the Board of Education's recommendations for revision of chapter 14 special education regulations.

Introduction

In December 2006, The Autism Society of Pennsylvania was most appreciative at being given the opportunity to present recommendations, within the rubric of the mandated process for the State Education Regulation revisions, on behalf of school-age Pennsylvanians on the autism spectrum. We were heartened that several of our suggestions were included in the Board of Education's published recommendations for changes to Chapter 14, such as retention of the Massachusetts autism language on items to consider for IEPs, and increased ESY protections and early eligibility. To us it was an indication of increased recognition by the Board that characteristics unique to autism require autism-specific additions and adjustments to the regulations and to state educational practices.

For the first time we began to feel that our efforts to provide input that would help assure appropriate education for our autistic children was valued by those entrusted with the responsibility to provide it.

You can imagine then our admixture of surprise and consternation regarding alterations that were made without warning to the Chapter 14 working drafts only minutes before the Board voted on passing its final draft. There was no opportunity for public discussion, hearings, or further Roundtable input regarding these unannounced changes.

The most disconcerting of the last-minutes changes regard the use of restraints and aversives on children in schools. If chapter 14 is approved in the Board's proposed form, it will contain a new clause allowing physical restraint of children for under 30 seconds at a time, as well as endorsing the use of prone restraint holds in Pennsylvania's schools under certain circumstances. These changes severely weaken Pennsylvania's wise and longstanding tradition of protecting school age children from harmful and even deadly restraints, and undermine our state's commitment to proven, research-based, positive behavioral practices.

Many among our ASA-PA constituency have experienced the fear of sending a child to school, knowing that a behavior incident or a misapplication of the child's behavior plan could trigger a physical altercation and subsequent restraint on the child.

Our members are aware that children with autism have been killed by well-meaning educators and law enforcement officials who do not recognize the dangers associated with restraining a terrified, struggling, and often language impaired autistic child, who might also be physically impaired and/or medically fragile.

Imagine not being able to speak, not understanding social interactions, being afraid and suddenly having someone try to hold you down. Our children cannot and will not know how to respond to such restraint, other than by struggling to the point of exhaustion or unconsciousness. Such brutal restraint procedures are forbidden in residential care and treatment facilities for special needs Pennsylvanians of all ages. Why then should they be permitted to be vested upon school children?

The current regulations demand that schools hold a meeting within 10 days after an incident of restraint occurs. The new regulations, without explanation, remove this 10 day mandatory meeting, thereby denying parents the opportunity to participate in preventative planning for a child who has been restrained. We believe that the removal of this mandatory meeting will result in situations where parents will not be fully notified of incidents of restraint of their children. We suggest, reasonably, for those who removed this necessary meeting requirement to imagine, just for a moment, that the child involved is theirs.

The changes to the regulations are unacceptable – they will almost certainly lead to injuries and even deaths of children in the autism community. We have therefore added a new section to our comments that includes language defining best practice in the use of restraints and aversive techniques in schools.

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The recommendations below are key areas that we urge you to reexamine.

The burgeoning incidence of autism, 1 in 150 births, has increased the challenge of the mandated burden upon our state education system to provide education appropriate to the needs of students with autism. These additional recommendations, like those you've accepted, are offered to reduce this burden. They are logical, reasonable, and consistent with the Board of Education's function of putting in place standards and practices most likely to ensure appropriate education for all children in our state.

Use of physical restraints in schools

Restraint and aversive techniques pose a particular risk to individuals with autism. ASA-PA endorses the recommendations of the VALUE Coalition regarding the need to revise the language concerning restraints and positive behavior interventions in 22 Pa Chapter 14. The VALUE Coalition's well-reasoned, research-based position statement sets forth this recommendation with great clarity.

The Special Education Appeals Panel and oversight of the Office of Dispute Resolution (ODR).

At the roundtables for chapter 14, multiple comments were given regarding difficulties with the neutrality and with oversight of the Special Education Appeals Panels. The PA school board association and disability and parent advocate groups, uniformly called for the removal of the appeals panel and for a return to a single tier, streamlined efficient system for holding special education due process hearings and appeals. The March 14th draft of Chapter 14 regulations eliminated the special education appeals panel as requested. Inexplicably, the appeals panel was re-added to the regulations in the final draft.

We continue to recommend that the Special Education Appeals Panel should be eliminated. If it is not eliminated, we request increased oversight for the panel, as follows

- Currently ODR is guided by an advisory Panel that meets once a year. The minutes of the advisory panel meetings are not open for public review, nor are the meetings open for public comment. We request that the workings of the ODR advisory panel become open for public comment and review.
- Currently there is one member of the 15 person special education appeals panel who in a 2 year period authored 24% of Appeals Panel decisions. It is clear that individual, Perry Zirkel, is not neutral in his application of the law. This is well-known in the special education community. Consider the decisions of Perry Zirkel, analyzed over a 2 year period:
 - o he reduced compensatory education for parents in 10 cases and increased it minimally in 2 cases, for a net balance of a reduction in compensatory education by 5,211 hours.

- o he granted parental exceptions in only 12% of cases, while District exceptions were granted in 71% of cases.
- o he cites his own journal articles or reviews for legal authority to motivate his decisions in 48% of cases! (25 separate citations in 2 years.)

ODR must be revamped so that it may be perceived as a neutral and fair body in determining special education case outcomes, which presently it is not. It is patently obvious that no one with a demonstrated bias should serve on the Appeals Panel or hold a contract as a hearing officer. There must be a mechanism for aggrieved individuals to file complaints and register comments with ODR. This must be done in order to assure fair and just handling of grievances, complaints and comments from affected parties.

Evaluation Timelines:

• We respectfully request that the Board reconsider the proposal that Pennsylvania allow 60 school days for a special education evaluation. We have prepared a rank-ordered summary of the IDEA evaluation timelines for each of the 50 states, plus the District of Columbia (see **Appendix A**). Pennsylvania's proposed regulations leave it tied in 50th place for how long it would take to evaluate our students suspected of a disability. Ten states have timelines approximately half as long as Pennsylvania's. Each day a child is waiting to be evaluated is a day of appropriate education lost to that child. (§14.123 & §16.22(i)).

Definition of Autism:

The definition of autism should be modified in the Regulations to explicitly include the entire spectrum, including autism, PDD-NOS, Asperger's Syndrome, High Functioning Autism, and Rhett Disorder. If the definition does not include the entire spectrum, then individualized services can never be appropriate. ('Definitions').

Disciplinary Considerations:

Children with autism have social delays and behaviors that can put them at grave risk for inappropriate disciplinary actions, such as repeated suspensions. Disability manifestations can result in criminal charges and incarceration. The following requirements will reduce the likelihood of damaging disciplinary measures:

- require a functional behavior assessment and IEP meeting anytime a student is referred to police. (§14.133).
- require inclusion of autism as a category where any removal from education for a disciplinary reason is a change in placement under §14.143, (the same as the category of mental retardation.)
- require that Parents must be invited to any team training or consultations involving behavior support planning. (§14.133)
- require disability specific training in the area of behavior supports for all staff. (§14.133)
- require access for BHRS (behavior and mental support services and staff) for schools, per the BHRS plan. (§14.133)

Transition Imperative:

• Require that an OVR representative be invited to be part of the IEP team for students of transition age. Most effective transition services are offered in real world, competitive employment and volunteer settings in the community or onsite vocational settings. (§14.131)

Extended School Year Imperative:

• Require ESY services be consistent with all IEP goals, and allow for social and recreational experiences with non-disabled peers to the fullest extent appropriate. (§14.132)

Gifted with Disability:

• Many students with autism are mentally gifted or have gifted areas of strength. Chapter 14 and 16 regulations must state that students may not be denied access to gifted programming or accelerated or enriched placements owing to a disability. Compliance complaints for gifted students with disabilities must be fully investigated. Identification procedures for gifted students must ensure that nonverbal, research based practices are employed to assess the cognitive strengths of students with autism without penalizing the students for their disability. (§16.22-3, §16.32 and we suggested adding a new section to chapter 14 regarding dually exceptional students.)