

## JRC'S EXPERIENCE WITH NEW YORK'S CHILD-SPECIFIC EXCEPTION PROCESS AS OF MAY 10, 2007

### New York State Department of Education's Regulations on the Use of Aversives<sup>1</sup>

On June 23, 2006, the New York Board of Regents adopted a set of "emergency"<sup>2</sup> regulations that severely restricted the use of aversive therapy with New York school children. These regulations had been proposed by the New York State Department of Education (NYSED). On January 9, 2007, the Board of Regents adopted a revised set of these regulations which were made permanent and which took effect on January 16, 2007.

On August 16, 2006, a group of what eventually became fifty New York parents, whose children's treatment had been adversely affected by the emergency regulations, filed a federal lawsuit seeking to enjoin the Board of Regents and NYSED from carrying out those regulations. The parents

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<sup>1</sup> *Aversives* refers to a subset of behavioral punishment procedures, used largely as an alternative to the use of psychiatric drugs in the treatment of individuals with major behavior disorders. The term includes such procedures as the application of a brief mild shock to the surface of the skin of the arm or leg as an immediate consequence for a behavior. Aversives are employed in the treatment of self-abuse, aggression and other seriously harmful behaviors. Aversives are used as supplementary procedures when behavioral rewards alone are insufficiently effective by themselves to accomplish effective treatment. There are now over 110 published papers in professional literature supporting the use of aversives.

<sup>2</sup> The emergency regulations were stimulated by a lawsuit for money damages that a former JRC parent and her attorney filed against her local school for placing her child at JRC. The lawsuit was without foundation. The mother had given her informed written consent for the use of aversives, the aversives had been approved by a Massachusetts Probate Court judge, the mother had allowed aversives to be used on her son in her own home, and her son had benefited significantly from them. However, in February 2006 her attorney, accompanied by an undercover New York City television newsman (Tim Minton), had appeared at JRC and demanded that JRC stop using the aversives. (JRC complied immediately. The student regressed, and eight weeks later the student was removed from JRC and placed in a state psychiatric hospital.) Immediately after the visit from the lawyer and the television newsman, both of them generated a spate of local and national coverage. It appears that this coverage caused NYSED, which had purchased JRC's services, including the use of aversive therapy, for 30 years, to panic and propose regulations to ban or make impractical the continued use of aversives. The entire story of this case is told at <http://www.judgerc.org/xxsummary.pdf>.

succeeded in obtaining a temporary restraining order that prevented NYSED from carrying out the parts of the regulations that were most problematic for the treatment of their children.

The regulations had sought to place the following restrictions, among others, on the use of aversives:

1. The regulations limited the use of aversives to the treatment of aggressive and self-abusive behaviors, thereby forbidding their use to treat destructive behaviors (such as destroying a computer or television set), noncompliance (such as refusing to attend school or comply with directions from a parent or teacher), major disruptive behaviors (such as public disrobing, public masturbating and screaming throughout the school day in one's classroom) and other behaviors that severely interfere with educational and social development. Fortunately, the 50 JRC parents who filed the federal lawsuit were able to obtain a temporary restraining order that prevented this provision from taking effect.<sup>3</sup>
2. The regulations made aversives much more difficult to use by requiring that each proposed use should go through a child-specific exception process in which a panel of paid consultants to NYSED would have to give a recommendation to the child's school district as to whether the use of aversives with that

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<sup>3</sup> On August 16, 2006, a group of JRC's parents that eventually numbered 50, as well as JRC, filed a lawsuit in the United States District of Northern New York seeking to enjoin NYSED from enforcing these regulations on their children. Many of these parents had seen their children suffer significant regression when the regulations went into effect. On three separate occasions, the judge ruled in favor of these parents, granting them restraining orders that kept NYSED from enforcing the most restrictive parts of these regulations (including restricting their use to the treatment of aggressive and self-abusive behaviors) until the court renders its decision on their request for a permanent injunction. The trial on that injunction is expected to be held in 6-9 months.

child should continue to be included in the child's Individual Education Plan ("IEP");

3. The regulations completely forbid the use of aversives for any new student who may need them, even for a life-saving purpose, after 2009;

In this paper we review the results of the child-specific exception process and its impact on the Judge Rotenberg Center's ("JRC") students to date.

### JRC's Experiences with the Child-Specific Exception Process

As soon as the regulations were passed, JRC submitted requests for child-specific exceptions for 37 students<sup>4</sup>. The requests were submitted to the children's local school district in New York. All but two or three of these requests were submitted prior to February 1, 2007.

In response to these 37 submissions, we have received 1 approval, 15 denials<sup>5</sup>, and 1 partial approval.

In the case of the partial approval, the panel denied approval for using skin-shock to treat health dangerous behaviors -- the behavior for which we really needed the use of an effective

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<sup>4</sup> It should be noted that all 37 of these applications that had already undergone JRC's extensive set of protections to insure careful and proper use of aversives. This means that each case had already been approved, on an individual case-by-case basis, by a Massachusetts Probate Court after appointing an attorney to represent the child's interests, and after enabling that attorney to hire a psychologist to advise him on the appropriateness of JRC's request to include aversives in the child's treatment plan. Each case had also already been approved by the child's parents, by JRC's Human Rights and Peer Review Committees, as well as by a physician and psychiatrist. In addition, the use of aversives had been approved the child's Individual Education Plan team and had been incorporated in the child's Individual Education Plan.

<sup>5</sup> Under the NYSED regulations the Committees on Special Education (CSEs) can either accept or override these denials by these panels.

aversive because that behavior was occurring frequently in the student in question. At the same time, the panel granted approval to use the skin-shock for aggression -- a behavior for which we did not need the aversive as much because the behavior was occurring only infrequently in that student. Therefore the partial approval was really a denial of the approval that we needed and should be counted as another denial, making a total of 16 denials.

The effective results to date, therefore, regarding JRC's applications for child-specific exception requests have been these:

37 applications submitted  
16 denials  
1 approval  
20 cases of no response

In summary, out of 17 responses, 16 (94%) were recommendations against granting the needed child-specific exceptions.

NYSED has made it a practice to not give JRC any information about any aspect of the child-specific exception process. The only information that has been provided to JRC has come from those local school districts that were friendly or professional enough to provide it to us. Consequently as to the 20 cases of no responses, what occurred could have been something such as the following: (1) the school district never submitted the child specific exception request to NYSED; (2) NYSED did not forward the request to a panel; (3) the panel did not render a decision; (4) NYSED did not inform the CSE of the panel's decision; and (5) the CSE did not inform JRC of the panel's decision.

One reason why the child-specific panels have been rejecting almost every single exception request is that the panels have pursued their responsibilities in a remarkably uninformed manner. They have never communicated with JRC's clinicians to discuss the cases. They have never observed or interviewed the student. And they have never discussed the cases with the parents. The failure of the clinicians on the panel to even interview the student before making their evaluations on the issues in question is a serious ethical failure.

Of all of the students for whom we sought a child-specific exception, one of the most deserving was a frail little girl from Long Island who had detached both retinas by head-hitting prior to enrolling in JRC. Once she had the benefit of aversive therapy, she stopped her head-hitting and was able to have her retinas re-attached. For this girl, therefore, the use of aversive therapy made the difference between being blind and having sight. Despite this clear-cut benefit of aversive therapy, this girl's child-specific panel refused to recommend the continuation of aversive therapy!

The cursory procedures followed by the members of the child-specific panels should be contrasted with the careful and thorough process followed by the Massachusetts Probate Courts in reviewing JRC's applications for court approved, detailed treatment plans in which aversives are requested. The opposing attorney employs, at the state's expense, a skilled psychologist who has years of experience in advising on JRC treatment requests. That psychologist reviews the plan, meets with the child at JRC, discusses the case with JRC clinicians and other staff members, and advises the attorney on the appropriateness of JRC's plans. An impartial judge then makes the final decision as to what should be included.

## Actions by the Sending School Districts to Remove Aversives from the Students' IEPs

Once it became clear to the Committees on Special Education<sup>6</sup> ("CSEs") that NYSED was now formally against the use of aversives, many of the CSEs appear to have felt a kind of political pressure to take an aggressive posture regarding the use of aversives at JRC. As a result, a number of CSEs called for IEP meetings at which they removed the use of aversives from the IEPs of the JRC students who came from their district. In other words, they did not even bother to wait to see if the Child-Specific Panel would recommend aversives for the children from their district. They simply removed the aversives on their own initiative with little or no discussion about the specific child in question.

This action caused the parents to have to incur enormous efforts and legal expenses to pursue appeals in order to keep the aversives from being removed from their children's IEPs.

One CSE member indirectly admitted the pressures it was under by telling JRC, in effect, the following, with respect to three students for whom JRC wanted to keep aversives in their IEPs: "We cannot approve aversives for all three. We will keep aversives for \_\_\_\_\_. As to the other two students, we'll approve the aversives for only one of the two. You can pick whichever one you want to be able to continue to receive the aversives."

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<sup>6</sup> The Committee on Special Education (CSE) is a committee that includes the local special education officials and the parent. It is responsible for developing and revising as needed the child's Individual Education Plan for meeting the child's educational needs.

At another recent CSE meeting, the school district officials agreed that a student had made significant progress through the use of aversive therapy, decreasing his total number behaviors that are treated with aversive therapy from 122 per month in 2001 to 4 per month for the first 4 months of 2007. Even when presented with this overwhelming evidence of the effectiveness of this treatment for this child, the district would still not agree to place aversive interventions in the IEP, nor even apply to the panel for a child-specific exception.

### Summary

The results, to date, of the child-specific exception process have not been encouraging. The persons appointed to be on these panels have not been required to be neutral on the issue of aversives. They have not been either knowledgeable or experienced in the use of aversives. They have not shown enough interest in their work to bother to communicate with the JRC clinicians, to meet the student whose lives their opinions might affect in a major way, or to communicate with the child's parents.

As a result the recommendations of the child-specific panels, which have recommended against aversives in 94% of the cases, have not served to protect students from a misuse of aversives. Instead, those decisions have prevented students from receiving needed and some cases life- and limb-saving therapy.

An unexpected further result of the child-specific exception process is that it has sent a silent but effective political directive to many of the CSEs - - to the effect that they should now remove aversives from their students' IEPs even before

hearing what the recommendations of the child-specific panels might be. As a result, scores of parents whose children were doing beautifully with the benefit of safe and effective aversive therapy have had to incur time, effort and legal expenses in appealing the decisions of their CSEs as well as in participating in a federal lawsuit to try to prevent the regulations from taking effect.

The NYSED regulations on aversives have had the effect of removing the decisions about the use of aversive therapy from the hands of the parents and the children's clinicians and placing them, instead, in the hands of persons many of whom find it important to keep in the good graces of the New York State Department of Education. This includes the consultants who have been hired and paid by that Department to serve on the child-specific exception panels and the local special education officials who are under the administrative regulations of NYSED and who are unable to place children in special schools unless NYSED is willing to provide the funding.

In short, for New York State students the process of approving aversive therapy -- a form of treatment that is admittedly not considered "politically correct" by those who lack knowledge and understanding of the subject -- is now largely in the hands of persons who are subject to political influence. The child's parents who, after all, have the most important stake in whether their child progresses or not, have been essentially removed from the decision-making process. And the professionals who have been working closely with the students for years, overseeing the use of aversive where needed, have not even been consulted.

A far better approach is the one used in Massachusetts, where an independent judge, who is far less subject to political pressures than are members of the child-specific panels or NYSED itself, and who is not beholden to any politically-appointed head of a state agency, makes a decision about whether aversive therapy should be authorized. The judge does this after each side has presented its case with the help of its own professional experts and the judge then reviews the case every six months thereafter to insure that the aversives continue to benefit the child.