DEPARTMENT OF DEVELOPMENTAL SERVICES

RESPONSE TO TESTIMONY AND WRITTEN COMMENTS TO PROPOSED AMENDMENTS TO BEHAVIOR MODIFICATION REGULATIONS

115 CMR 5.14

October 14, 2011

DDS' Response to Testimony and Comments on Proposed Amendments to Behavior Modification Regulations

The Department of Developmental Services ("the Department") announced its intention to promulgate amendments to its existing behavior modification regulations, 115 CMR 5.14, on or about June 8, 2011. Pursuant to the provisions on M.G.L. chapter 30A, the Department thereafter held public hearings on July 20, 2011 and July 22, 2011 to take testimony and receive public comment on the proposed regulations.

The Department conducted two days of public hearings in venues across the state. It heard the testimony of national, state and local disability advocacy organizations, human rights organizations, clinicians and professionals serving individuals with disabilities and severe behavioral challenges, provider organizations, a union whose members serve individuals with disabilities, family members of persons with intellectual disabilities, autism and other disabilities with challenging behaviors, attorneys representing such individuals and others.

The overwhelming number of written comments received by the Department were in support of the proposed regulations. Of a total of 287 written comments[1] received, 272 were in support of the proposed regulations and 15 were opposed to the proposed regulations. Of a total of 97 oral comments, 24 people submitted their comments in writing as well. Of the 73 unduplicated oral comments, 15 were in support and 56 were opposed to the proposed regulations[2]. All of the comments opposed to the regulations came from individuals affiliated with the Judge Rotenberg Center ("JRC") including approximately 59 JRC employees, 2 attorneys, 9 family members and one former student.

The written comments received from national and state associations were overwhelmingly in support of the proposed regulations, of particular note being the President's National Council on Disabilities, the American Association on Intellectual and Developmental Disabilities (Massachusetts Chapter), the ARC of Massachusetts, the National Association of State Directors of Developmental Disability Services, the Association of Developmental Disability Providers, the Massachusetts Developmental Disabilities Council, MA Advocates Standing Strong, the Providers Council, TASH and many others. None of the oral or written comments received from national or state organizations opposed the proposed regulations

[1] Includes one petition supporting the proposed amendments to regulations signed by 23 people; 24 people submitted additional written comments or information supplementing their initial written comments. The Department did not include these additional submissions in its count of comments received.

[2] The position regarding the proposed regulations of two of the commenters was not clear from their testimony.

Public Comments Received

The Department received oral testimony from 97 individuals and over 275 written comments in response to the proposed regulations. Many individual comments were submitted by persons who either work with individuals with disabilities (from providers including Advocates, American Training, Inc., Association for Community Living, BAMSI, Inc., Brockton ARC, Community Systems, Inc., Delta Projects, Employment Resources, Inc., the Judge Rotenberg Educational Center, Life Works, Lifelinks, the May Institute, Minuteman ARC, North East ARC, North Shore ARC, North Suffolk Mental Health, People, Inc., Shore Collaborative, Seven Hills, TILL. Inc., Vinfen, and Work, Inc.) and from family members of persons with disabilities.

In addition, the Department received comments from various organizations representing individuals with intellectual disability including:

American Association on Intellectual and Developmental Disability (AAIDD), Massachusetts Chapter

American Association on Intellectual and Developmental Disability (AAIDD), Region X Board

The ARC of Massachusetts
217 South Street
Waltham, MA 02453

Association for Community Living
One Carando Drive
Springfield, MA 01104-3231

Association of Developmental Disabilities Providers (ADDP)
1671 Worcester Road (Rt. 9W), Suite 201
Framingham, MA 01701 .
Phone: 508.405.8000
Fax: 508.405.8001

Autism National Committee

Citizens Commission on Human Rights

Community Alliance for Ethical Treatment of Youth (CAFETY)
1101 15th St. NW, Suite 200
Washington, DC 20005

Council of Parent Attorneys and Advocates, Inc. (COPAA)
PO Box 6767
Towson, MD 21285

Massachusetts Developmental Disabilities Council
1150 Hancock Street, Suite 300
Quincy, MA 02169

Disability Policy Consortium
P.O. Box 77
Boston, MA 02133
mail@dpcma.org

International Coalition for Autism and All Abilities
200 Crestwood Plaza
St. Louis, MO 63126
Info@internationalautismcoalition.org

Massachusetts Special Education Administrators

Massachusetts Down's Syndrome Congress
20 Burlington Mall Road, Suite 261
Burlington, MA 01803

Massachusetts Advocates Standing Strong
500 Harrison Avenue
Boston, MA 02118

Massachusetts Office of the Child Advocate
The Honorable Gail Garinger (ret.)
One Ashburton Place -5th Floor
Boston, MA 02108

Mental Health Legal Advisors Committee
Supreme Judicial Court
24 School Street – 8th Floor
Boston, MA 02108

My Voice, My Choice of Mississippi

National Association of State Directors of Developmental Disability Services (NASDDDS)
113 Oronoco Street
Alexandria, VA 22314

National Council on Disability
1331 F. Street NW, Suite 850
Washington, D.C. 20004

National Disability Rights Network
Protection & Advocacy for Individuals with Disabilities
900 Second Street NE, Suite 211
Washington, DC 20002-3560

Providers' Council
www.providers.org

Service Employees International Union- Local 509
100 Talcott Ave.
Bldg 313, 2nd Floor
Watertown, MA 02472]

Stavros Center for Independent Living &
Disability Policy Consortium
210 Old Farm Road
Amherst, MA 01002

TASH
1001 Connecticut Avenue, NW, Suite 235
Washington, DC 20036

The Department also received comments from a number of clinicians and experts engaged in the treatment of persons with intellectual disability, autism and other disorders with very challenging behaviors, including:

Ann Cotter-Mack, BCBA, Director of Behavioral Services
TILL, Inc.
20 Eastbrook Road, Suite 201
Dedham, MA 02026-2056

Dr. Anne M. Donnellan, Professor
Director, USD-Autism Institute
University of San Diego
School of Leadership and Education Sciences
5998 Alcala Park, San Diego, CA 92110-2492

Dr. Sue A. Gant, Ph.D., Behavioral Psychologist
Gant, Yackel & Associates Inc.
2015 Parkview Dr.
Hawarden, IA 51023-1256

Dr. Wade Hitzing, Ph.D.
10455 Witmen Drive
Fort Meyers, Fl. 33919

Clinicians from the Judge Rotenberg Center including:
Dr. Nathan Blenkush, Ph.D., Director of Research,
Dr. James Riley, Ph.D., Director of Treatment
Jason Corderre, M.S. Ed., Clinician
Nicholas Lowther, M.A., BCBA, Assistant Clinical Director for Masters Clinicians
Dr. Susan Haydar, Ph.D., Clinician
Dr. Robert von Heyn, Ph.D, Director of Clinical Services

Elisabeth Stringer Keefe
Graduate Special Education Program
School of Education
Lesley University
Cambridge, MA

Gary W. LaVigna, Ph.D., BCBA-D
Clinical Director, Institute of Applied Behavioral Analysis
5777 W. Century Blvd- Suite 675
Los Angeles, CA 90045

Martha R. Leary, M.A., Reg. CASLPA, CCC-SLP
Halifax, NS
B3P 1Y3
Canada

Cynthia Levine, Behavior Specialist

Dr. Nirbhay N. Signh, Ph.D.
American Health & Wellness Institute
PO Box 5419
Midlothian, VA 23112
(retired) Professor of Psychiatry, Pediatrics and Psychology
Virginia Commonwealth University School of Medicine
Richmond, VA

Dr. Dina Traniello, Ph.D., Educational Consultant

Dr. James Waters, Ph.D.
Director of Psychology
Wrentham Developmental Center
131 Emerald Street
Wrentham, MA 02093

Dr. Christopher T. White, Ed.D., CEO
Road to Responsibility
1831 Ocean Street

Marshfield, MA 02050

The Department also received a number of comments from attorneys familiar with or involved in representing individuals and/or organizations in the field of disabilities, and in particular behavioral treatment for person with disabilities including the following organizations:

Disability Law Center
11 Beacon Street
Boston MA 02110

Center for Public Representation
246 Walnut Street
Newton, MA 02460
info@cpr-ma.org

Mental Health Legal Advisors Committee
24 School Street – 8th Floor
Boston, MA 02108
MHLAC@mhlac.org

Counsel for the Judge Rotenberg Center
Michael P. Flammia, Esquire
Eckert Seamans Cherin & Mellott, LLC
2 International Place, 16th Floor
Boston, MA 02110
http://www.eckertseamans.com

Counsel for Families at the Judge Rotenberg Center
Henry W. Clark, Esquire
Clark, Hunt, Ahern & Embry
55 Cambridge Parkway
Cambridge, MA 02142

The Council of Parent Attorneys and Advocates (COPAA)
P.O. Box 6767
Towson, MD 21285

The Department also received comments from a number of individual self-advocates and the self-advocacy group Massachusetts Advocates Standing Strong (MASS).

The Department also received testimony from Massachusetts State Senator Brian A. Joyce.

Research Review

Prior to publishing the proposed regulations, the Commonwealth reviewed and considered scientific literature regarding both positive behavioral supports and punishment as behavioral interventions to treat problematic behavior in individuals with intellectual disability and related conditions. Several important conclusions can be drawn from the published research regarding each.

First, there have been many articles published in professional journals regarding positive behavior supports and interventions over the last two decades establishing the efficacy of positive behavior interventions and supports in reducing problem behaviors in children and adults with intellectual disabilities. See e.g. *Carr, E.G., et al. Positive Behavior Support for People with Developmental Disabilities: A Research Synthesis, American Association on Mental Retardation, 1999, pp 66-68*. In *Carr et al*'s. review of literature published in the American Journal of Mental Retardation (now the American Journal of Intellectual Disability), for example, researchers concluded that positive interventions were effective in reducing problem behavior in one half to two thirds of all cases and that success rates nearly doubled when the intervention was based upon a prior functional assessment.

Researchers surveying the published literature between *Carr et al.'s* study and 2005 found that "assessment-based PBS [positive behavior supports] interventions have continued to be effective in significantly reducing the problem behavior of individuals with severe disabilities . . (cites omitted)." *See Snell, Martha E., Fifteen Years Later: Has Positive Programming Become the Expected Technology for Addressing Problem Behavior? A Commentary on Homer et al*. (1990), Research & Practice for Persons With Severe Disabilities Vol. 30, No. 1, at 13.

In contrast, "basic research on punishment has been declining rapidly despite substantial gaps in knowledge (cites omitted)" *Lerman, Dorothea C. and Vorndran, Christina M., On the Status of Knowledge For Using Punishment: Implications for Treating Behavior Disorders, Journal of Applied Behavior Analysis,* No. 4, p. 431, 2002.[3]

[3] Of the 30 total studies which have been published which investigated the effectiveness of contingent skin shock:

- Only 7 such studies have been published since 1977 (not exceeding one per year during any of the past 30 years);
- Only 7 articles have been published in the US in the 15 years
- Only 3 groups of U.S. researchers have conducted research in this area in 15 years.

Testimony of Dr. Fredda Brown, PhD, dated January 16, 2008 *submitted to the Massachusetts Legislative Joint Committee on Families, Children and Persons with Disabilities in connection with Hearing on House 1904 (an act creating and authorizing level IV behavioral treatment intervention).*

Further, with regard to the research regarding the durability of treatment with punishment, research results are varied. *See Lerman, et al.* at 447-451. "A number of authors, however, have suggested that the clinical effects of punishment are relatively short-lived, even when the treatment remains unchanged over time." *Id* at 447. "Basic findings on the maintenance of the response suppression following the termination of the punishment contingency also showed that the response rates immediately returned to pre-punishment levels – sometimes even temporarily exceeding baseline - unless intense punishers were used (e.g. high-voltage shock; Azrin, 1960)." *Id*.

Several commenters opposed to the regulations pointed to a recent study published by clinicians from the Judge Rotenberg Center, *Israel, M.L. Blenkush, N.A. von Hyen, R.E. & Rivera, P.M. (2008) Treatment of aggression with behavioral programming that includes supplementary skin shock. The Journal of Behavior Analysis of Offender and Victim Treatment and Prevention (JOBA-OVTP)*, 1(4), 119-166. Commenters cited the study as supporting "a 100% success in the treatment of aggressive (sic), using a criterion of 90% reduction from baseline for all 60 individuals that started on GED between 2003 and 2006." *Id*.[4]

Testimony From Clinical Experts

In written and oral comments, several experts also addressed whether the use of punishment to treat maladaptive behaviors was consistent with the standard of practice in the field. Representative excerpts from these comments are reproduced below:

One commenter who has authored or co-authored over 100 books, chapters, articles and monographs concerning the treatment of behavioral disorders in persons with intellectual disability, in addition to practicing in the field, commented as follows:

> *"I have not used painful aversives and electro-shock in my entire professional experience in over 35 years of consulting to governments and programs responsible for serving persons with disabilities, many [of whom] are considered to have extreme behavioral challenges… It is my professional opinion that the use of such techniques is unnecessary, unacceptable and not supported by the professional literature. Alternative interventions and approaches have been more successful in reducing or eliminating dangerous or self-injurious behaviors and, notably, do not contribute to a problem behavior increase post-treatment. My experience is shared by peers and colleagues across the United States, Canada, England, Ireland, Australia and New Zealand. The experience is reflected in*

[4] In the cited article, the authors claim that the positive behavioral treatment, supplemented with contingent skin shock, is approximately "twice as effective in treating aggression as were the positive behavioral supports cited in the Carr et al.1999 report." With respect to long-term effectiveness after removal of the contingent aversive, however, the authors noted that "[a]lthough gradual removal or fading of the GED was possible for many (38%) [study] participants, CSS treatment may, for some individuals with significant developmental disabilities, be prosthetic, i.e. required on a long-term basis …rather than curative." (*Israel et al., 2008* at 157). Thus for 62% of the study participants contingent skin shock was successful in reducing behaviors only so long as it was continuously applied or available.

research and hard data that positive supports are more appropriate and effective than painful aversive techniques."

Dr. Anne M. Donnellan, Professor
Director University of San Diego
Autism Institute
Professor Emerita, University of Wisconsin, Madison

Another commenter noted:

"I am writing to strongly support the proposed regulation amendments… [f]urther, I would urge you to go further and eliminate the use of all Level III aversive altogether.

The evidence-based research and practice data are quite clear that punishment or aversive contingencies of any form do not teach but rather suppress behaviors for short periods of time and have no positive long-term effects. The data show that punishment and aversive contingencies do not inform children how to behave or improve their learning. . . Why we continue to use disproven technologies is a sad commentary on our social system. There is an abundance of data showing positive reinforcement methods can teach children, even those with severe and profound learning problems, how to behave, learn, and have a good quality of life."

Dr. Nirbhay N. Singh, Ph.D.
American Health and Wellness Institute and
(Retired)Professor of Psychiatry
Virginia Commonwealth University

Another clinician stated:

"We [the Institute for Applied Behavioral Analysis] have been providing services for 30-years and support hundreds of people who are considered to have the most challenging behavior. … The approach we have developed at IABA precludes the need for any punishment procedure, let alone contingent shock. In fact, we are often referred people for whom punishment has been tried and failed. Here is what we have found and what is supported by professional literature:

Punishment is unnecessary for reducing the occurrence of problem behavior and as an after the fact strategy is inherently flawed.

Positive alternatives, such as antecedent control, are far superior.

Punishment has the added likelihood of increasing episodic severity, a new measure of behavioral outcomes, which should be required of any legislation governing the use of restrictive behavioral procedures. See [Lavigna, G. and

Willis, T., "Episodic Severity, An Overlooked Dependent Variable in the Application of Behavioral Analysis to Challenging Behavior," Journal of Positive Behavior Interventions , Vol. 7, Winter 2005, pages 47-54. ...]

Based upon [my experience] and based upon the extensive published research in this area, there is no clinical support nor empirical justification for the extreme aversive, punitive procedures authorized by the Massachusetts' regulations, particularly the use of contingent skin shock."

Gary W. LaVigna, Ph.D., BCBA-D
Institute for Applied Behavior Analysis

Another commenter stated:

"When I began working with individuals with developmental disabilities in the late1960s the use of punishment procedures to manage challenging behaviors such as aggression or self-injury was not uncommon. We routinely used physical and mechanical restraint not just to keep the person safe but also as a negative consequence, as punishment. When less intense punishment did not decrease the problem behavior we upped the ante and restrained or secluded the person for longer and longer periods, took away more privileges, etc. While it was never a common practice, we sometimes even resorted to the use of pain to control severely self-injurious behavior…

Thankfully, most states have since passed laws/regulations that banned the use of painful punishers. This required us to develop more positive ways to effectively deal with dangerous behavior. We have learned that punishment can only teach a person what <u>not</u> to do and is effective only so long as we continue to punish. We have learned that the most effective way to help a person gain control over his /her behavior, especially over the long term, is to deal with the real causes for the challenging behavior…

In the past 30 years I have worked in, consulted with, evaluated and monitored at least one hundred programs that served individuals with severe behavior challenges and dangerous behavior, in more than 20 states. None of them have allowed the planned use of pain to control the individuals' behavior.

Wade Hitzing, Ph.D.
10455 Witmen Drive
Fort Meyers, Fl. 33919

Another behavioral psychologist with over 40 years in the field of developmental disabilities echoed the support for non-aversive interventions and commented on the lack of evidence-based support for the use of aversives:

"In all of the years of serving, supporting, and evaluating behavior supports for many persons in the United States and a U.S. Territory, who have the most severe behavioral challenges, I have never had occasion to use painful aversives and electro-shock. I have consistently employed various, less restrictive and non-painful behavior management techniques, which usually have been successful, at least when implemented in a consistent and careful manner by qualified staff, in reducing or eliminating dangerous or self-injurious behaviors….Colleagues in other States, service systems, and programs around the country have developed a consensus, based upon empirical research and extensive clinical data, that positive supports rather than painful aversive techniques are the most successful and appropriate response to challenging behaviors... the aversive techniques currently authorized by the Department's regulations. . . is so inconsistent with the professional literature and research data on effectiveness as to warrant immediate revision… the Department's proposed prospectively (sic) ban the use of these aversive interventions is long overdue, but entirely supported by the professional consensus of disability professionals who specialize in behavior analysis and support."

Dr. Sue A. Gant
Gant, Yackel and Associates, Inc.

Other clinicians commented in support of aversive interventions, in particular contingent skin shock. The Department considered the testimony of a clinician associated with the Judge Rotenberg Center:

I am the Director of Clinical Services at the Judge Rotenberg Center where I have worked for nearly 22 years. All clients have a right to effective treatment and an outright ban on aversives would deny them this right. I have seen hundreds of individuals benefit from this treatment…This is a scientifically validated treatment for individuals with severe behavior disorders who have not responded to other less intrusive forms of treatment. The oversight of this treatment at JRC has been extensive and in-depth…

The literature on the treatment of severe behavior disorders contain clear evidence that positive only programming does not work for everyone. A review of the studies that summarized the effectiveness of positive-only treatments, reports that a 90% reduction is found, at best, in 60% of the individuals treated. What happens to the other 40%? In most cases that we have found, high doses of medications are used and in some cases they are ejected by the treatment facility they were in and sent to JRC. JRC has published a peer-reviewed journal article describing 7 of these individuals. In most cases this is not [sic] form of treatment but rather clinical restraint the side effects of medications are well known, and worst case, fatal. JRC recently published a study that reports a 100% success in the treatment of aggressive [sic], using a criterion of 90%

reduction from baseline, for all 60 individuals that started on GED between 2003 and 2006. No other treatment has ever produced that level of success over such a short period of time. A 2008 publication, in a peer reviewed journal, reported no negative side effects of treatment, and any side effects were either neutral or positive.

Dr. Robert E. von Heyn, PhD
Judge Rotenberg Center

The Department considered the comments of another clinician from the Judge Rotenberg Center, who wrote:

As a clinician who has worked with difficult-to-treat individuals with severe behavior disorders for over 10 years, it is with sadness, confusion and anxiety that I read the recent DDS-proposed regulation amendments that would remove aversive therapy as a treatment choice for individuals with disabilities…How is DDS suddenly now sure that some combination of 'non-aversive' therapies/measures will <u>always</u> be effective in keeping <u>every</u> person safe relative to severe (e.g. life-threatening, organ or tissue-damaging) self-abuse and severe aggression? Has DDS recently reviewed an established and replicated scientific research base that indicates that <u>every</u> individual's quality of life, dignity, independence and freedoms will be increased with positive-only treatment technologies? Has DDS spoken with clients and their families and heard those clients and families state that they no longer wish to have this treatment choice? . . .

Aversive Therapy ≠ Torture

…Used as a clinical treatment last resort (that supplements intensive positive/less restrictive treatments), with rigorous oversight by multiple professional disciplines (including Medical Doctors, Nurses, and Licensed Psychologists), with parental consent, with human rights committee approval, with Peer Review Committee approval, and with court approval, it is not logical to equate aversive treatment with torture…

In many cases, the addition of aversive therapy to individual's behavior programs was either life-saving or life-changing (e.g. the client could go into their community safely and visit their family safely whereas these were not possible before). In either case…the results for the client were incredibly positive…

The proposed DDS regulatory changes risk [a] dangerous and ineffective treatment scenario for individual citizens with developmental disabilities.

Nicholas Lowther, M.A., BCBA
Judge Rotenberg Center

Testimony from Organizations and Associations

The Department also considered testimony from many national, state and local organizations representing individuals with intellectual disability or their families. All the organizational commenters supported the proposed regulations, although some felt that they should go further in excluding all aversive treatment.

Excerpts from comments from leading advocacy organizations are noted below:

The American Association on Intellectual and Developmental Disabilities is a leading research and advocacy organization dedicated to serving individuals with intellectual disability. The Massachusetts Chapter of the AAIDD wrote:

> *"Research indicates that aversive procedures such as deprivation, physical restraint and seclusion do not reduce challenging behaviors, and in fact can inhibit the development of appropriate skills and behaviors…Research-based positive behavioral supports should be readily available in natural settings, including the family home."*

Jean Phelps and A. Michael Bloom
Board, Region X, AAIDD

The Department considered testimony from the ARC of Massachusetts, another leading national and state advocacy organization:

> *"The DDS regulatory changes are based on the current research in the field. This research demonstrates that aversive procedures are not regarded to be effective methods of permanently altering behavior, including behavior which may be self-abusive. Other, non-invasive methods, which pose no risk to an individual's well-being, have been developed. Such methods have been demonstrated to be effective, not only during the period in which they are applied, but after the intervention is withdrawn. To reinforce our comments we have included . . . the "Position Statement on Behavioral Supports" adopted by both The ARC and the AAIDD (American Association on Intellectual and Developmental Disabilities)".*

The ARC
Christopher Andry, PhD, President
Leo Sarkissian, Exec. Director

The Department considered the following comments from the Massachusetts Provider's Council:

> *"The Council understands the difficulty for many concerned parents who are seeking an effective treatment for their loved ones and have resigned themselves to this form of treatment. However, we support the statements*

of the Massachusetts Disability Law Center, Inc. which challenges the assumption that this is the best treatment option. We also support the position of the American Network of Community options and resources (ANCOR) that "Behavioral interventions that withhold meals, essential nutrition and hydration, intentionally inflict pain, use chemical and other restraint in lieu of positive programming; or which involve the employment of techniques which produce physical or psychological pain , humiliation and discomfort must be eliminated."

Providers Council
Human Services Providers' Charitable Foundation, Inc.
250 Summer Street., Ste. 237
Boston MA 02210

Less Restrictive Requirement: Potential for Overuse of Level III

The Department notes that under current regulations, programs that utilize Level IIII aversives must satisfy the requirement of demonstrating attempts to use a less restrictive intervention and that Level III aversives may only be used to treat dangerous behaviors. 115 C.M.R. 5.14 provides:

> No Interventions shall be approved in the absence of a determination, arrived at in accordance with all applicable requirements of 115 CMR 5.14, that the behaviors sought to be addressed may not be effectively treated by any less intrusive, less restrictive Intervention and that the predictable risks, as weighed against the benefits of the procedure, would not pose an unreasonable degree of intrusion, restriction of movement, physical harm or psychological harm. . . .
>
> Level III Interventions may be used only to address extraordinarily difficult or dangerous behavioral problems that significantly interfere with appropriate behavior and or the learning of appropriate and useful skills and that have seriously harmed or are likely to seriously harm the individual or others.

With regard to these requirements, several commenters noted that once aversive interventions are approved for treating an individual's behavior(s) there is a tendency to increase clinical reliance upon aversive for controlling all behaviors, not just those that are highly dangerous, and that prohibiting aversives will lead providers of treatment to find less restrictive and intrusive methods to mange problematic behaviors:

> *"The license to shock, hit and hurt becomes a self-fulfilling prophecy…programs that believe that people need to be shocked, hit and hurt to change their behavior will find justifications for doing so. They invite an abuse of authority and power struggles between children and staff in which children invariable risk being tortured or tormented into submission. This means of trying to change behavior can become a contagious coping mechanism for over-stressed staff. Once staff*

are authorized to hit or shock residents, initially in response to behaviors that are characterized as 'dangerous,' there is a continual tendency to broaden that authorization to other conduct, including so-called 'pre-cursor behaviors,' until the entire focus of the program becomes the use of pain to achieve control. Programs that believe such conduct is abusive and abhorrent will and do find other non-harmful ways to manage and change the same behavior."

Clarence J. Sundrum
Special Master for the Federal Court,
District of Columbia
Former Chairman of New York State's Commission on Quality of Care for the Mentally Retarded and (former) President of the board of Directors of Mental Disability Rights International

The Department considered testimony from several witnesses who spoke about the potential for abuse with aversives. The Department considered the testimony of a Massachusetts state legislator who commented upon a reported incident which occurred in August of 2007 in which there was an unauthorized application of 77 contingent skin shocks to one individual and 28 contingent skin shocks to another by non-clinical staff for behaviors that had not occurred and, even if they had, were not dangerous.

Comments Regarding the Capacity to Address Severe Behavioral Problems Without Using Aversives

The Department also considered the testimony of provider groups such as ADDP and the Providers' Council, and of a union. These organizations collectively represent over 30,000 employees providing services to individuals with intellectual disability, autism and related disorders in Massachusetts. Both the provider associations, and a major employee union, the Service Employee International Union (SEIU), opined that it was possible to provide safe supports to individuals with these challenging behaviors without resorting to aversives.

One commentator pointed to a "a wide range of clinicians in Massachusetts using a range of successful treatment alternatives" including Horace Mann Educational Associates, Melmark, New England, Amego, Vinfen, Delta Projects, the May Institute, Community Resources for Justice, Justice Resource Institute and Alternatives Unlimited."

Attorney Frank Laski
Massachusetts Mental Health Advisory Committee

Many providers themselves offered testimony in support of the proposed amendments including: United Cerebral Palsy of Berkshire; Bridgewell; TILL; BAMSI; Partners: Community Systems, Inc.; North Suffolk Mental Health: Work, Inc.; Shore Collaborative; Life Works; Behavioral Health Network; United Cerebral Palsy (Boston); NorthEast ARC; Seven Hills; Minute Man ARC; Vin Fen; Employment Resources, Inc.;

the May Institute; American Training: LifeLinks; Stavros Center for Independent Living; SEIU; Quabbin Valley Educational Consultants and Delta Projects.

Some providers addressed their ability to serve individuals with severe behavior disorders without using aversives. Some representative excerpts are:

> *"As the board-certified behavior analyst working with developmentally disabled individuals for 33 years . . . and as the Director of Behavorial Services for TILL, Inc., I have stopped the practice of Level II procedures . . .*
>
> *Other, non-aversive methods, which pose no risk to an individual's well-being, have been developed Such methods have been demonstrated to be effective not only during the period when they are applied, but after the intervention is withdrawn."*

*Ann Cotter-M*ack
Till, Inc.

A state and its local union chapter offered this testimony:

> *"Our membership collectively has extensive experience in a variety of settings working with individuals with behavioral challenges on the front lines. We believe that through positive behavioral supports and other techniques individuals with significant behavioral challenges can and are being served effectively without the need to resort to . . . the (Level III) behavioral interventions or skin shock."*

Susan Tousignant, President SEIU
Stu Dickson, SEIU 509

Another provider wrote:

> *"The Association, founded in 1952, provides residential and family supports to over 1000 individuals with developmental disabilities and their families, in western Massachusetts. In our services are a number of people with severe behavioral challenges. We do not use aversive interventions, such as those that would be restricted by these regulatory changes."*

Barbara Pilarcik, Executive Director
The Association for Community Living

In response to the assertions made in the hearings that aversives were the treatment of last resort for individuals who were expelled or discharged from schools and providers that could not effectively treat their behaviors, several other commenters noted that while

aversives *may* have been the only available, effective treatment thirty years ago, the progress in the field of behavioral science has eliminated the need for it to treat the most serious behaviors.

> *"…in 1987, positive approaches to behavior modification were in their infancy…In 2011, there are effective evidence-based individual and community alternatives to the use of restraint, seclusion, and aversive behavioral interventions."*.

Mathew Engel, Attorney
Disability Law Center

Testimony and Comments from Individuals and Family Members Opposed to the Regulatory Change

The Department also considered testimony in opposition to the proposed regulatory change. The Department notes that in the testimony from the JRC's employees, many of whom had worked at JRC for many years, staff would relate stories about individuals who were admitted and treated with aversives only after the failure of other treatment options (e.g. being heavily medicated, etc.) In essence, aversive treatment was related as the last resort for such individuals and produced, according to staff, positive results. This testimony was reiterated by JRC's counsel, Michael Flammia, in his oral and written comments.

The Department considered the testimony of JRC staff opposing the proposed regulations who emphasized that aversive treatment was only appropriate for a small number of individuals with the most severe behavioral challenges.

These commenters noted the comprehensive process necessary to obtain court approval to implement a behavior plan containing Level III aversive interventions as a safeguard to misuse of this treatment. In addition, these commenters stressed that Level III aversive treatment is incorporated into a primarily positive behavior intervention treatment program and that alternative programming is not effective for everyone. These commenters also asserted that Level III aversive treatment is the only recourse for a small number of people with severe behaviors, and that without such interventions, there would be a need to utilize mechanical and chemical restraints to control behavior, which may subject individuals to severe side effects.

The Department also considered testimony from nine guardians and family members of individuals at JRC and comments as well as from counsel for the Judge Rotenberg Center Parents Organization. These families strongly urged that families of children at JRC should be able to choose to allow for JRC to use the GED to administer skin shocks as part of treatment for their children.

The Department heard testimony from a former JRC client who indicated that his treatment with the GED (skin shock) assisted him to discontinue behavioral difficulties that had not been successfully treated with medications or alternative schooling.

Finally, some commenters from JRC noted that aversive interventions are utilized to address behaviors in students or individuals who do not respond to alternative treatments at other facilities. These commenters asserted that the GED is an effective, safe (no side effects) alternative when positive behavioral interventions and medication are not effective. They argued that the use of the GED allows people to access educational and community activities that they otherwise could not.

Prospective Versus Complete Ban on Aversives

The proposed amendments would limit the utilization of Level III aversive interventions for those individuals who did not have a court-approved treatment plan by September 1, 2011. Under the proposed regulations, those individuals who did have a court-approved behavior plan that included aversives would be permitted to continue to receive those treatments, subject to other regulatory requirements. 115 CMR 5.14.

Many commenters who voiced their approval for the proposed amendments also urged the Department to expand the prohibition to prohibit all aversives regardless of the existence of a court-approved plan. *Association for Community Living, Office of Child Advocate, TASH, Mental Health Legal Advisors Committee* ("…we urge the Department to eliminate the proposed exception for those residents with court-ordered treatment plans in effect by September 1, 2011. That exception allows for the indefinite continuation of the use of electric shock aversives on a population of disabled individuals…"); *Decker, Mental Health Legal Advisors Committee, National Disability Rights Network* ("NDRN believes that in situations where the individual has an existing court-approved treatment plan which permits the use of Level III behavior interventions, the continued use of Level III behavioral interventions should not be extended beyond one year."); *McClennen/AUTCOM* (limit court approvals to a one year period); *Marshall/COPAA* ("… that exemption must be time limited, and in no case authorized for a period in excess of 6 months").

Other States' Policies Regarding Aversive Interventions

A review of the other forty-nine states and the District of Columbia indicates that 21 states specifically "ban" or prohibit aversive interventions through statutes, regulation or policy: Alabama, Arizona, Arkansas, Colorado, Connecticut, District of Columbia, Florida, Illinois, Indiana, Maryland, Michigan, Missouri, Montana, Nevada, New Mexico, Oklahoma, Pennsylvania, Rhode Island, South Dakota, Vermont, and Washington. Our review further indicated that other states have informally adopted practices of using positive only supports and, in practice, have banned the use of aversive interventions; we located no state whose practice includes the use of aversives such as contingent skin shock.

Conclusion

The Department "shall adopt regulations which establish . . . procedures and the highest practicable professional standards for the … treatment" of individuals with intellectual disability. G.L. c. 123B, § 2. After careful deliberation, the Department finds that the current standard of care for individuals with intellectual disability with the most severe behavioral challenges is positive behavior intervention and does not include aversive interventions or punishment. The Department concludes that there has been an evolution in the treatment of severe behavioral disturbances in persons with intellectual disability over the past thirty years, and particularly in the last two decades, which has moved towards forms of treatment that are non-aversive and involve positive behavioral supports.

The Department bases this opinion both on the body of empirical evidence showing the effectiveness of other less intrusive forms of treatment that do not involve pain; on the overwhelming support of this position by virtually every local, statewide or national organization supporting individuals with intellectual disability, and by providers and clinicians whose practice demonstrates that non-aversive treatment can modify difficult or dangerous behaviors effectively and for the long-term, while aversive interventions, in addition to causing pain and anxiety in such individuals, have no proven long-term efficacy.

The Department further concludes, based upon the testimony of experts in the field, and based upon the Department's experience with Level III programs, that the approval of Level III aversives, intended only for behaviors that pose a serious risk of harm, tends to increase reliance of staff upon these interventions, and leads to the application of Level III interventions to non-dangerous behaviors.

The Department concludes that not only is the proposed restriction on the use of aversives consistent with the prevailing standard of care in the field of intellectual and developmental disabilities, there is capacity within the state to provide effective behavioral treatment to individuals with the most severe behavioral challenges without using aversive procedures. There exists an array of providers who currently effectively provide non-aversive behavioral supports to such individuals.

With regard to requests for a broader "ban" on aversives, the Department recognizes that many guardians and family members of individuals receiving this form of treatment believe, based upon their past experience, that aversives are the only effective form of treatment for their loved one(s). While the Department does not agree, the history of extensive litigation over access to painful stimuli as treatment should not and need not be repeated here. The Department believes that by leaving aversives in place for this limited group of individuals, it will be an important step towards moving the system of services towards more positive, non-aversive treatment.

In this regard, the Department notes that under the proposed regulations, individuals with an existing (as of September 1, 2011) court-approved behavior plan that includes Level

III aversive interventions will continue to be able to receive this treatment so long as it continues to be court-approved.

For those commenters who asked whether the proposed regulations would prohibit the use of aversives for an individual who had a court-approved behavior treatment plan as of September 1, 2011, but who was "faded" from aversives such that they were removed from his or her plan, and then subsequently needed them again, the Department takes the position that such an individual would continue to have access to aversives. In our view, a contrary rule would discourage "fading" from Level III aversives.

Two commenters questioned whether the proposed regulatory change would apply to all persons receiving aversives, or just those with "intellectual disability[5]." The Department is the only state agency that by regulation permits the use of aversives; any provider thus seeking to use aversives, whether for children in a residential setting or through licensing of a school program, relies upon the Department's certification. Thus, under the current regulations, the ability to utilize aversives for individuals with intellectual disability or autism, or any related disorder, is derived from the Department's regulations which are intended to apply to all facilities licensed by the Department.

The Department concludes that the proposed amendments shall be promulgated with an effective date of October 30, 2011.

Commissioner Elin M. Howe

[5] Some other commenters appear to interpret the terms intellectual disability and developmental disability interchangeably.