
**COMMONWEALTH OF MASSACHUSETTS
SUPREME JUDICIAL COURT**
NO. SJC-13298
(Appeals Court No. 2021-P-0730)

THE JUDGE ROTENBERG EDUCATIONAL CENTER, INC, *et al.*,
Plaintiffs-Appellees.

v.

**COMMISSIONERS OF
THE DEPARTMENT OF DEVELOPMENTAL SERVICES AND
THE DEPARTMENT OF EARLY EDUCATION AND CARE,**
Defendants-Appellants.

ON DIRECT APPELLATE REVIEW OF THE
BRISTOL PROBATE COURT'S DENIAL OF A RULE 60(b)(5) MOTION TO
VACATE A CONSENT DECREE IN No. BR86E0018-G1

BRIEF OF THE ARC OF MASSACHUSETTS, DISABILITY POLICY
CONSORTIUM, MASSACHUSETTS DEVELOPMENTAL DISABILITY
COUNCIL, FEDERATION FOR CHILDREN WITH SPECIAL NEEDS, AND
MASSFAMILIES AS AMICI CURIAE IN SUPPORT OF THE APPELLANT,
THE DEPARTMENT OF DEVELOPMENTAL SERVICES

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April 3, 2023

CORPORATE DISCLOSURE STATEMENT

Pursuant to Supreme Judicial Court Rule 1:21, *amici curiae* certify that none of them is a publicly held corporation, that no amicus has a parent company, and that no publicly held corporation owns a 10% or more ownership interest in any of the *amici*.

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INTRODUCTION

State and federal agencies, disability professionals, provider associations, family groups, consumer run organizations, and even the United Nations have unequivocally disavowed the use of contingent electric shock precisely because it violates legal, ethical, and professional standards for the care and treatment of people with disabilities. The Judge Rotenberg Center (JRC) is the only program in the United States where these shock devices are manufactured and used.

Contingent electric shock is not “treatment.” It is not supported by modern treatment theories, and as determined by the federal Food and Drug Administration (FDA), devices like the Graduated Electronic Decelerator (GED) create a substantial risk of injury and harm with no reliable evidence of long-term efficacy.

Amici are Massachusetts organizations composed of, or operated on behalf of, persons with disabilities and their families. They support the Commonwealth’s statutory and regulatory authority to ban level III aversives, including the GED, and its efforts to vacate the 1987 Consent Decree. They describe how significant changes of fact and law surrounding the care and treatment of people with disabilities, including those with intellectual and developmental disabilities (I/DD) and aggressive or self-injurious behaviors, make continued enforcement of the Consent Decree inequitable and contrary to the public interest.

INTEREST OF AMICI¹

The Arc of Massachusetts

The Arc of Massachusetts (The Arc) is the Massachusetts affiliate of The Arc of the United States, the nation's largest community-based organization of and for people with I/DD. The Arc represents the interests of more than 200,000 children and adults with I/DD in the Commonwealth. It advocates for community supports and services that foster social inclusion, self-determination, and equity across all aspects of society. Through its legal advocacy and public policy work, The Arc promotes and protects the human and civil rights of people with I/DD.

Disability Policy Consortium

The Disability Policy Consortium (DPC) is an organization of persons with disabilities who share a common goal of equal opportunity for all individuals with disabilities. The DPC's mission is to ensure the voice of people with disabilities is heard on key issues, to support the health of the disability community through participatory research and expert policy analysis, and to empower grassroots disability leaders to transform their communities. DPC advocates at the legislative and policy level to ensure people with disabilities have equal access to the health care, programs, and services they need to live integrated lives in the community.

¹ Pursuant to Mass. R. App. P. 17(c)(5), *amici* declare that no party or counsel for a party authored this brief in whole or in part and that no person other than *amici*, its members, or its counsel has made any monetary contributions intended to fund the preparation or submission of this brief.

Massachusetts Developmental Disability Council

The Massachusetts Developmental Disabilities Council (MDDC) is an independent agency whose members are comprised of individuals with developmental disabilities and their family members. MDDC is dedicated to empowering people with developmental disabilities to lead independent, self-sufficient lives in the community. It works to eliminate attitudinal barriers to inclusion and promotes opportunities for people with developmental disabilities to impact public policy through self-advocacy.

Federation for Children with Special Needs

The Federation for Children with Special Needs (FCSN) began in 1975 as a Statewide parent coalition and later grew into a national movement with approximately 100 Parent Training and Information Centers (PTIs) across the United States and territories. FCSN advocates for quality education, strong parent participation, and access to quality health care services for all children, especially those with disabilities. The Federation plays a pivotal role in the dissemination of information, support, and assistance to culturally and linguistically diverse parents of children with disabilities, their professional partners, and their communities.

MassFamilies

MassFamilies is a grassroots membership organization comprised of people with disabilities and their families, allies, and supporters. Their mission is to

provide sustained advocacy and leadership training in pursuit of high-quality, individualized community support and service options for people with disabilities and their families. MassFamilies engages in a wide array of activities, including training, technical assistance, and policy advocacy, designed to promote responsive, high-quality, individualized community supports and services that are family and person-centered.

STATEMENT OF THE ISSUES

Amici adopt the Statement of the Issues as set forth in Appellant’s Brief.

STATEMENT OF THE CASE

Amici adopt the Statement of the Case as set forth in Appellant’s Brief.

STATEMENT OF THE FACTS

Amici adopt the Statement of the Facts as set forth in Appellant’s Brief.

SUMMARY OF THE ARGUMENT

The Massachusetts Rules of Civil Procedure require, and courts in Massachusetts and throughout the country have consistently held, that consent decrees must be terminated when significant changes in fact would make prospective application inequitable or detrimental to the public interest. In 2011, the Department of Developmental Disabilities (DDS) properly exercised its statutory authority to prohibit the prospective use of level III aversive interventions, like contingent electric shock, in all its licensed and certified programs. In doing so, it adopted the overwhelming view of disability experts,

State agencies, and national professional organizations that such aversive interventions are dangerous, ineffective, and inconsistent with professionally accepted standards of care. However, DDS has been prevented from enforcing these regulatory requirements against the JRC, due to the Trial Court's expansive and impermissible reading of the 1987 Consent Decree.

In its 2018 decision, the Court abused its discretion in several respects and committed reversible errors of law. First, it disregarded the limited purpose of this Decree and the applicable constraints of separation of powers by concluding, in effect, that DDS can be indefinitely precluded from regulating the use of specific aversive interventions within its licensed facilities and programs. Second, the Trial Court erred in concluding that the substituted judgment process allows probate courts to authorize interventions that a controlling State agency – DDS in this case – has banned as unsafe and ineffective.

Finally, the Trial Court diverged from the applicable legal standard under Rule 60(b) by requiring a demonstrated professional consensus on the use of Level III aversives, rather than a significant change in fact regarding the safety and efficacy of these interventions and the standard of care for people with I/DD and challenging behaviors. The Court further erred by excluding compelling evidence of this change in the standard of care collected by the FDA and published in the Federal Register. Continuing developments post-trial, including the FDA's issuance of a final rule banning the use of electric shock devices for people with

aggressive and self-injurious behaviors, and the position of professional organizations within the Applied Behavior Analysis (ABA) field, further underscore the extent of these changes in fact and their impact on accepted standards of care for persons with I/DD. For these reasons, continued enforcement of the Consent Decree is inequitable and detrimental to the public interest. As a result, the Trial Court’s order should be reversed, and the Decree vacated.

ARGUMENT

I. The Trial Court Erred in Interpreting the 35-Year-Old Consent Decree as an Indefinite Constraint on DDS’s Statutory Authority to Regulate Interventions in Its Licensed and Funded Programs.

A. The purpose of the Consent Decree was to permit JRC to continue to operate a licensed treatment program, not to permanently preclude DDS from regulating the use of new aversive interventions like contingent electric shock.

The original Consent Decree – entered in 1987 – was a narrowly tailored, time-limited, court-enforceable settlement agreement.² Although it did not foreclose the development of new aversives, the Consent Decree did not, and could not, permanently abrogate DDS’s authority to regulate the future use of those interventions, particularly if evidence suggested that new aversive interventions

² *Behavior Research Institute, et al., vs. Mary Kay Leonard, et al* Civil Action No. 86E-0018-GR, Superior and Probate Court Departments, Bristol (approved Jan. 7, 1987) (hereafter “Consent Decree”). The Consent Decree was to automatically terminate after two six-month review periods, unless the Court, “for good cause shown related to the terms or substance of this agreement, ordered otherwise,” *id.* at 15, but was later extended indefinitely by the Court, pending further orders.

were harmful and ineffective. Rather, its sole purpose was to resolve pending litigation stemming from the Massachusetts Office for Children's (OFC) 1985 order to show cause why the license of the Behavior Research Institute (BRI) should not be suspended, revoked, or otherwise sanctioned for various violations of OFC's regulations.³

The Consent Decree makes clear that BRI must comply with all Department of Mental Health (DMH) (the predecessor of DDS) regulations concerning restraint, human rights committees, and periodic review of individualized education and service plans.⁴ This Court affirmed such a reading of the Consent Decree in *Judge Rotenberg Educ. Ctr. v. Commissioner of the Dep't. of Mental Retardation*, 424 Mass. 430 (1987) finding that “there is no provision in the agreement that provides the department gave up *any* regulatory authority.” *Id.* at 445 (*abrogated on other grounds, In re Birchall*, 454 Mass. 837 (2009) (emphasis added). This Court went on to note that, “...to read the agreement as a delegation of all regulatory authority would implicate serious constitutional issues.” *Id.* at 445-46.

³ Consent Decree at 2 (“The sole intent of each party is simply to resolve this case and the other administrative and judicial cases which are now pending between O.P.C., B.R.I. and the parents.”). OFC was a predecessor of DDS. JRC was previously called BRI.

⁴ Consent Decree at 10.

The “most intrusive, most restrictive” interventions in use when the Decree was entered were spanks, pinches, muscle squeezes, and time out while restrained. Neither the GED III nor the subsequent and more powerful GED IV – both electric shock devices developed and manufactured by JRC – were in existence until many years later, making it impossible to anticipate or evaluate the potential dangers associated with their use.⁵

As discussed below, the Trial Court’s reading of the Consent Decree as an indefinite constraint on DDS’s exercise of its statutory and regulatory authority to curtail dangerous or ineffective aversive interventions is overbroad, impermissible, and inconsistent with principles of separation of powers, justifying termination.

B. As interpreted by the Trial Court, the Consent Decree undermines the exercise of DDS’s statutory authority to oversee the care and treatment of individuals with disabilities.

The Massachusetts Legislature has conferred upon DDS expansive authority over the health and welfare of individuals with I/DD and the facilities and programs which provide them services and supports. DDS is mandated by the Legislature to:

[T]ake cognizance of all matters affecting the welfare of persons with an intellectual disability or persons with a developmental disability. The department shall have supervision and control of all public facilities for persons with an intellectual disability and of all persons received into any of

⁵ As noted in Section III, *infra*, the existence of a significant change in the standard of care for people with disabilities, and particularly those with serious behavioral challenges, has only become clearer since the trial on the Commonwealth’s motion to vacate.

said facilities, and shall have general supervision of all private facilities for such persons...

G.L. c. 19B § 1.

The term “take cognizance” in the first sentence of G.L. c. 19B § 1 indicates a broad grant of statutory authority “of all matters affecting the welfare of the persons with an intellectual disability.” *See Williams v. Executive Office of Human Services*, 414 Mass. 551, 567-68 (1993) (statute requiring DMH to “take cognizance of all matters affecting the mental health of the citizens of the commonwealth” permits DMH to exercise discretion to determine priorities for allocation of resources among services, where the enabling statute does not itself clearly establish particular priorities); *see also, Attorney General v. Dime Sav. Bank of New York, FSB*, 413 Mass. 284 (1992); *Woodbridge v. Worcester State Hospital*, 348 Mass. 38, 41 (1981) (regulations governing the “right to skillful, safe, and humane treatment” and “governing the use of restraint and seclusion” adopted pursuant to G. L. c. 123, § 2, inserted by St. 1970, c. 888, § 4, the predecessor statute governing both DDS (then DMR) and DMH). If the Court were to decide that this language did not provide authority to DDS regulate the type, nature, and quality of appropriate services, it would call into question the

authority of numerous other State health care agencies to issue regulations central to their core mission.⁶

DDS's broad mandate specifically includes the authority to regulate treatment when necessary to protect the rights, interests, and safety of some of the Commonwealth's most vulnerable citizens. DDS has the sole authority to license adult residential and day services,⁷ and to prohibit or limit the use of various interventions like restraint, seclusion, punishment, and painful aversive conditioning in its licensed and certified programs. *See* G.L. c. 19B, § 15(a)-(e). Further, DDS is charged with protecting the health and safety of individuals in those programs. Specifically, DDS shall:

Adopt regulations ... which establish procedures and the highest practicable professional standards for the reception, examination, *treatment*, restraint, transfer and discharge of persons with an intellectual disability in departmental facilities. Said regulations shall be adaptable to changing conditions and to advances in methods of care and treatment and in programs and services for persons with an intellectual disability.

G.L. c. 123B § 2 (emphasis added). DDS has exercised this statutory authority to regulate and proscribe treatment interventions in its State operated and licensed programs where there is evidence that those interventions are potentially

⁶ *See, e.g.*, G.L. c. 19, § 1 (DMH); G.L. c. 115, § 5 (Department of Public Health); G.L. c. 111E, § 2 (Division of Drug Dependency).

⁷ Each facility licensed by the department "shall be subject to the supervision, visitation and inspection of the department..., (and) [t]he department may refuse to grant, suspend, revoke, limit or restrict the applicability of or refuse to renew a license granted under this section...." G.L. c. 19B, § 15(c), 15(d).

dangerous, harmful, or outside of acceptable standards of care by restricting the use of potentially harmful interventions like restraint,⁸ and prohibiting the practice of seclusion.⁹

In 2011, after engaging in rulemaking pursuant to G.L. c. 30A and receiving input from a wide range of national and local experts, disability professionals, family members, and service providers, DDS updated its regulations to reflect significant changes in professional treatment standards for people with I/DD. *See* Section II.A, *infra*. These regulations banned the prospective use of “level three aversives” including contingent electric shock. 115 CMR § 5.14A, et seq. Individuals receiving electric shock pursuant to a court-ordered treatment plan developed prior to September 1, 2011, were exempt from this regulatory prohibition consistent with existing judicial orders. 115 CMR § 514.A (4)(b)(4).

The 2011 regulations also established comprehensive standards of care with respect to mistreatment, restraint, seclusion, and behavior modification. Under G.L. c. 123B, § 2 and G.L. c. 19B, §15, there is ample statutory authority for DDS’s adoption and enforcement of these regulations, including the State’s police power to regulate health, safety, and the general welfare, and its *parens patriae* power to protect vulnerable citizens, neither of which can be validly curtailed by

⁸ *See, e.g.*, 115 CMR 5.02 (prohibiting physical restraint in a prone position); 115 CMR 5.11(1) (limiting restraint to “emergency” situations).

⁹ 115 CMR 5.14(15)(a)(5).

the Consent Decree. *See, e.g., Anusavice v. Board of Registration in Dentistry*, 451 Mass. 786, 795 (2008) (where board's policy “is not contrary to the language of its enabling statute and is rationally related to furthering the board's purpose to safeguard the public health and welfare, it will be upheld”). *Accord, Levy v. Board of Medicine*, 378 Mass 519, 525 (1979). “Where the means of fulfilling that obligation is within the discretion of a public agency, the Courts normally have no right to tell that agency how to fulfill its obligation.” *Commonwealth v. Carrara*, 58 Mass. App. 86, 89 (2003).¹⁰ As reflected in its enabling statute, DDS is best positioned to adopt regulations that reflect professional judgment about what treatments are safe, effective, and consistent with evolving clinical standards of care. This responsibility to protect health and safety, and to issue regulations and policies on appropriate treatment interventions, cannot be delegated or surrendered in a consent decree.

However, some probate courts have refused to prospectively enforce the DDS regulations in individual cases and the Trial Court has concluded that the regulations are impermissible under the Consent Decree. *See, e.g., Decision on Motion to Dismiss, Guardianship of S.B., (Impounded)*, No. BR12P0811GD (Bristol Probate & Family Ct., Field, J.) (May 14, 2014) at 5-6 (DDS’s 2011

¹⁰ In *Carrara*, the Appeals Court characterized a district court order requiring a hospital escort as “impermissible ‘poaching by the judicial branch on executive...territor[y].’” *Id.* at 91 (citation omitted).

Regulations could not be reconciled with “the terms of the [Decree],” and “directly interfere” with JRC’s ability to administer aversives). JRC Add. 264-5; discussed in the Appellant’s July 2022 Brief at 28 n. 10.¹¹ By interpreting the 35-year-old Consent Decree as an indefinite and judicially imposed restriction on DDS’s regulatory authority, the Trial Court contravenes the General Court’s mandate, and jeopardizes the health, safety, and welfare of individuals with severe disabilities. As a result, it constitutes an abuse of discretion and must be reversed.

II. DDS Can Prohibit Harmful, Dangerous, or Ineffective Interventions Without Intruding on Massachusetts’ Substituted Judgment Process.

A. The Trial Court erred in concluding that the substituted judgment process provides an avenue for approving unauthorized treatment modalities or overriding State agency determinations of what constitutes an unsafe and ineffective intervention.

Substituted judgment proceedings provide an equal opportunity for incapacitated persons to choose among otherwise lawful treatment interventions. Through a judge's exercise of substituted judgment, the State meets its obligation to “recognize the dignity and worth of [the incapacitated] person and afford to [the incapacitated] person the same panoply of rights and choices it recognizes in competent persons.” *Rogers v. Commissioner of the Dep’t of Mental Health*, 390

¹¹ Public court records available from the attorney portal on www.massCourts.org show recent probate court orders authorizing level three aversives for individuals who were not receiving GED pursuant to a Court-ordered treatment plan prior to September 1, 2011, thereby directly contravening DSS regulations. *See, In the Matter of Winters, Erica* NO11P2896GD (Norfolk Probate and Family Court); *Matter of E.W.*, No. NO19P3030GD (Norfolk Probate and Family Court); and *Matter of G.A.* No. WO14P1885GD (Worcester Probate and Family Court).

Mass. 489, 499–500 (1983), quoting *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 746 (1977). As such, substituted judgment acts as a proxy for choice and consent.¹²

Substituted judgment cannot expand the scope of choices available to incapacitated persons beyond that which is available to people with decision-making capacity. *Cf. Charrier v. Charrier*, 416 Mass. 105, 110 (1993) (court order requiring agency to provide services it is not obligated to provide usurps executive functions and violates separation of powers). Nor does it empower courts to approve the use of prohibited treatments on incapacitated individuals. Substituted judgment cannot be used by a probate court to authorize a medication or treatment prohibited by the FDA,¹³ or to sanction the use of seclusion which is banned by State regulation.¹⁴ Such an impingement on State statutory and regulatory authority would override the considered judgment and expertise of agencies like

¹² Most reported substituted judgment cases discuss the right to refuse a *legal* form of treatment, not the right to obtain a prohibited form of treatment. *See e.g., Saikewicz*, 373 Mass. at 737 (decision to decline chemotherapy weighed against State’s interest in preservation of life, protection of third parties, prevention of suicide and preservation of ethical integrity of the medical profession.); *Matter of Spring*, 380 Mass. 629, 634 (1980) (a competent person has the right to refuse medical treatment; substitute judgment allows incompetent person to exercise the same choice). The applicable Massachusetts Uniform Probate Code section, G.L. c. 190B § 5-306A, has no provision to the contrary.

¹³ *United States v. Rutherford*, 442 U.S. 544 (1979) (holding that there is no express or implied exception under the Federal Food, Drug, and Cosmetic Act for unapproved drugs to be used by the terminally ill).

¹⁴ 115 CMR 5.14(15)(a)(5).

DDS which have a legislative mandate to protect the health and safety of vulnerable citizens. *See* Section I.B, *supra*. An incapacitated person cannot, through the substituted judgment process, consent to drugs, interventions, and services that are banned for use by a person with decision-making capacity. Such an application of substituted judgment would severely distort both the purpose and scope of that process.

The right to accept or reject treatment, and the range of choices available to health care consumers, is subject to reasonable State regulation. Drugs which have not been approved by the FDA, like interventions explicitly prohibited by State regulatory agencies, fall outside the universe of choices available to be made either directly, or through substituted judgment. As the 10th Circuit noted in *United States v. Rutherford*:

The decision by a patient whether to have a treatment or not is a protected right, but his selection of a particular treatment [for terminal cancer], or at least a medication, is within the area of governmental interest in protecting public health.

616 F.2d 455, 457 (10th Cir. 1980). Consequently, the probate court cannot, in exercising the substituted judgment of an incapacitated person, consent to treatment interventions which a State or federal agency has prohibited. *See generally, Custody of a Minor*, 378 Mass 732, 747 (1979) (affirming restriction on parents' medical decision-making for child and citing *United States v. Rutherford*, 442 U.S. 544 (1979) in best interests/substituted judgment analysis). Similarly, the

probate court would be prohibited from using substituted judgment to authorize physician-assisted suicide in contravention of State law. *See generally, Kliger v. Attorney General*, 491 Mass. 38, 66-70, 73 (2022) (distinguishing the right to refuse life-prolonging treatment established in Massachusetts' substituted judgment caselaw and holding that physician-assisted suicide is not among the fundamental rights protected by the Massachusetts Declaration of Rights).

Finally, substituted judgment is not intended to deprive incapacitated individuals of the protections of State law or to abrogate regulatory activities undertaken by the Commonwealth to protect the health and safety of its citizens. On the contrary, this doctrine is intended to provide a means of exercising and protecting the existing rights and liberties of incompetent persons. *See In the Matter of Moe*, 385 Mass. 555, 565 (1982) ("In utilizing the doctrine of substituted judgment, this Court seeks to maintain the integrity of the incompetent person by giving the individual a forum in which his or her rights may be exercised."); *Cf., Commonwealth v. DelVerde*, 398 Mass. 288 (1986) (holding that the constitutional right not to be tried while incompetent cannot be overcome through use of substituted judgment). *See also*, Liacos, "Is 'Substituted Judgment' A Valid Legal Concept?" 5 Issues L. & Med. 215, 218-20 (1989-1990); <https://go.gale.com/ps/i.do?p=AONE&u=googlescholar&id=GALE|A8042570&v=2.1&it=r&sid=googleScholar&asid=6f5a0972>.

For these reasons, the Trial Court erred in concluding that substituted judgment can be used to authorize lawfully banned interventions which the designated oversight agency of the Commonwealth has determined to be unsafe, ineffective, and outside the bounds of professionally accepted standards of care.

B. The constitutional principle of separation of powers further limits a probate court's authority to make treatment decisions that conflict with the executive branch's responsibility to regulate health and safety.

Limitations on the authority of a court derive not only from the nature of substituted judgment itself, but from Article 30 of the Massachusetts Declaration of Rights, which provides that “the judicial [branch] shall never exercise the legislative and executive powers....” Mass. Const. pt. 1, art. XXX. As this Court noted in a previous decision between these parties:

We recognize, of course, that “[a] Court ... may not properly exercise the functions of the executive branch of State government.” *Care & Protection of Isaac*, 419 Mass. 602, 605 (1995) ... Indeed, it is fundamental that a judge's order should and could not ignore the department's authority regarding certification requirements or compliance with applicable regulations. To do so would violate the principles of separation of powers by usurping an executive function (internal citations omitted).

Judge Rotenberg Educ. Ctr., Inc., 424 Mass. at 446.

Matter of McKnight, 406 Mass. 787, 791-792 (1990) made clear that the guardianship proceeding did not vest the probate court with authority to order a form of treatment, or a specific program placement, that is not otherwise available.

Similarly, in *Care & Protection of Jeremy*, 419 Mass. 616, 622 (1995), the Court concluded:

A grant of equitable jurisdiction is a grant of broad power to act in the best interests of a person properly within the jurisdiction of the Court. . . . That power, however, does not extend to “decid[ing] questions committed by law to the determination of public officials. . . .” (internal citations omitted).

See also Department of Mental Retardation v. Kendrew, 418 Mass. 50, 56 (1994)

(district court had no authority in a criminal proceeding to order defendants’ placement in a long-term residential program over DDS’s objection since gaps in the service system are not within the court’s power to fill and order for provision of services was not an ancillary judicial function of rule-making or judicial administration).

In sum, permitting the use of painful aversives on persons with disabilities through substituted judgment orders exceeds judicial authority in violation of Article 30 where such aversives are properly prohibited by regulation, and that prohibition is consistent with the State agency’s legislative mandate. The Trial Court’s failure to recognize this constitutional constraint on a probate court’s discretion requires reversal.

III. Termination is Warranted Given Significant Changes in the Standard of Care for People with I/DD and Serious Health and Safety Risks Associated with Electric Shock Devices.

A. The Trial Court’s application of an erroneous and unduly burdensome standard of review constitutes an abuse of discretion.

Rule 60 requires, and courts have consistently held, that consent decrees must be modified or terminated when significant changes in fact would make continued enforcement inequitable or otherwise detrimental to the public interest. *See* Fed. R. Civ P. 60(b); Mass. R. Civ. P. 60(b)(5).¹⁵ Federal courts consider changed circumstances a key factor in deciding whether to modify or vacate consent decrees. *Rufo v. Inmates of Suffolk County Jail*, 502 U.S. 367, 384 (1992). The First Circuit has held that a “significant change in the philosophical approach to treatment” can be a basis for modification of a consent decree. *King v. Greenblatt*, 149 F.3d. 9, 19 (1st Cir. 1998) (holding that the Department of Correction demonstrated a significant change in the treatment of civilly committed sexual offenders justifying a modification of a twenty-seven-year-old consent decree). The Court also considered that a majority of States had repealed or significantly reformed laws similar to Massachusetts, and that among professionals the “assumption that mental disability underlay sexual offenses in general was no longer viewed as clinically valid.” *Id.* at 20.

This Court similarly concluded that a consent decree may be modified or terminated when a “significant change in facts or law warrants revision of the decree.” *Macdonald v. Caruso*, 467 Mass. 382, 388-89 (2014), citing *Rufo*, 502

¹⁵ "As a general principle, the Massachusetts Rules of Civil Procedure are given the same construction as the cognate Federal rules" and, "[i]n all pertinent respects, Mass. R. Civ. P. 60(b) is identical to [Fed.R.Civ.P. 60(b)]." *Sahin v. Sahin*, 435 Mass. 396, 400 n.7 (2001).

U.S. at 393. Courts have the authority to provide relief from judgment when there are changed circumstances which make prospective application of the decree no longer equitable. Mass. R. Civ. P. 60(b)(5); *see also, Atlanticare Medical Center v. Division of Medical Assistance*, 485 Mass. 233 (2020) (concluding changed circumstances, including federal guidance and subsequent caselaw, require modification of judgment); *Clean Harbors of Braintree, Inc. v. Board of Health of Braintree*, 415 Mass. 876, 884-85 (1993).

Here DDS satisfied its burden by demonstrating a significant, widespread change in the standard of care for individuals with I/DD, the risks associated with GED, and the federal government’s decision to terminate federal Medicaid funding for services provided at JRC.¹⁶ However, rather than applying Rule 60(b)’s standard of significant change in fact, the Trial Court required that DDS demonstrate a professional consensus on the applicable standard of care. JRC Brief at 46 (Add. 155).¹⁷ The Court further abused its discretion by requiring that DDS prove the efficacy of less restrictive alternatives for JRC clients receiving level III aversives. *Id.* Such proof is not legally required by Rule 60; nor is it necessary given that the 2011 regulation grandfathered existing court-approved

¹⁶ *See generally* State Brief at 55-56; Ex. 319, Letter from Exec. Off. of Health and Hum. Ser., Off. Of Medicaid (December 2012).

¹⁷ “Defendants have failed to demonstrate that there is now a *professional consensus* that the Level III aversive treatment used at JRC does not conform to the accepted standard of care for treating individuals with intellectual and developmental disabilities.” (Field, J), Decision at 49 (emphasis added).

treatment plans. 115 CMR § 5.14A(4)(b)4. The Trial Court’s misapplication of the standard of review warrants vacatur.

B. DDS’ 2011 regulations are based upon significant changes in professional treatment standards for individuals with disabilities.

As evidenced by the public record associated with DDS’s rule making, there had been a significant factual change in the standard of care for individuals with I/DD by 2011. *See* Response to Testimony and Written Comments to Proposed Amendments to Behavior Modification Regulations (“Response to Comments”) 115 CMR § 5.14 (Oct. 14, 2011); <https://www.mass.gov/doc/department-of-developmental-services-response-to-testimony-and-written-comments-to-proposed/download>. The vast majority of written and oral testimony submitted to DDS during the rulemaking process spoke to the dangerous and dehumanizing nature of contingent electric shock, the lack of clinical evidence regarding its efficacy, and the availability of effective, less restrictive treatments. *Id.* at 2. A review of forty-nine States and the District of Columbia indicated that 21 States specifically “ban” or prohibit painful aversive interventions through statutes, regulation, or policy, and revealed no other State whose practice included contingent skin shock. *Id.* at 19.

A DDS research review also found a dearth of professional, peer-reviewed literature supporting the use of punishment to address challenging behaviors, including contingent electric shock. *Id.* at 7-8. In contrast, literature postdating the

Probate Court’s 1987 Judgment demonstrated the existence of safer, more effective alternatives, like Positive Behavior Supports (PBS). *Id.* at 20.¹⁸ Thus, the 2011 regulation reflects, and specifically incorporated, both a significant change in professional treatment standards and growing evidence that level III aversive interventions were harmful and unnecessarily restrictive.

A court must give “due weight to the experience, technical competence, and specialized knowledge” of the agency, as well as to “the discretionary authority conferred upon it.” *Magazu v. Department of Children and Families*, 473 Mass. 430, 437 (2016), citing G.L. c. 30A, § 14(7) and *Bulger v. Contributory Retirement Appeal Bd.*, 447 Mass. 651, 657 (2006). The DDS regulation at issue clearly meets this test. It was duly promulgated, informed by changes in professional standards of care, and consistent with DDS’ legislative mandate to ensure the proper treatment and safety of individuals in its State operated and licensed programs.

For these reasons, the Trial Court erred in concluding that DDS forfeited its statutory authority to ban the use of level III interventions under the 1987 Consent Decree, regardless of significant changes in the standard of care of individuals with challenging behaviors, and the availability of safer, effective, less restrictive alternatives.

¹⁸ DDS subsequently updated its regulations to ensure all programs which are operated, funded, or licensed by the Department employ PBS. 115 CMR 5.14(1)(b).

C. *The FDA’s lengthy rule-making process and extensive factual record supporting the ban of Electrical Stimulation Devices is further evidence of a significant change in the standard of care, justifying termination.*

In March of 2020, the FDA issued its final rule banning the use of Electrical Stimulation Devices (ESDs) on individuals who experience self-injurious or aggressive behaviors.¹⁹ In doing so, the FDA reaffirmed its conclusion in 2016 that ESDs presented an “unreasonable and substantial risk to public health”²⁰ and should not be used, even in individual cases where other treatments may not completely reduce or eliminate these behaviors.²¹

The supporting FDA record was exhaustively compiled over six years and two administrations, and included individual testimony, research from clinical experts, complaint data from JRC and DDS, professional standards from national disability organizations, and reviews of the professional literature. Extensive evidence underpinning the agency’s decision was collected between 2014 and 2016, cited in the proposed rule, and later incorporated into the final rulemaking.

¹⁹ See 85 Fed. Reg. 13312;

<https://www.federalregister.gov/documents/2020/03/06/2020-04328/banned-devices-electrical-stimulation-devices-for-self-injurious-or-aggressive-behavior>.

²⁰ U.S. Food & Drug Admin., FDA News Release (April 22, 2016);

<https://www.fda.gov/news-events/press-announcements/fda-proposes-ban-electrical-stimulation-devices-intended-treat-self-injurious-or-aggressive-behavior>.

²¹ Banned Devices; Proposal To Ban Electrical Stimulation Devices, 81 Fed. Reg. 24406 (Apr. 25, 2016);

<https://www.federalregister.gov/documents/2016/04/25/2016-09433/banned-devices-proposal-to-ban-electrical-stimulation-devices-used-to-treat-self-injurious-or>.

Although the D.C. Circuit Court of Appeals subsequently held that the FDA’s statutory authority did not extend to banning devices for specific purposes, it did not opine about the merits of the agency’s findings and conclusions.²² Moreover, the Appeals Court’s statutory interpretation has now been superseded by Congress’s recent amendment to the FDA’s statute, signed into law in late December 2022 as part of the federal spending bill. That legislative change clarifies that the FDA has the authority to ban devices for specific purposes.²³

The FDA’s administrative record clearly demonstrates that the overwhelming weight of professional research, and virtually all peer-reviewed scientific literature, supports DDS’s ban on the use of contingent electric shock and its subsequent motion for termination. *Amici* highlight several key aspects of the FDA’s extensive findings of fact.

First, the FDA determined that ESDs (like the GED) create “unreasonable and substantial risks of illness and injury,” with little or no credible evidence of efficacy or long-term benefit.²⁴ Risks of harm include pain, skin burns, loss of sensitivity to fatigue or pain, and injuries from falling, as well as psychological

²² *Judge Rotenberg Educ. Ctr., Inc. v. United States Food & Drug Admin.*, 3 F.4th 390, 394 (D.C. Cir. 2021) (rehearing en banc denied Nov. 22, 2021) (concluding in a 2:1 panel decision that the FDA does not have the statutory authority to partially ban devices for a particular use).

²³ Consolidated Appropriations Act, 2023, Pub. L. No. 117-328, § 3306, amending 21 USCA §360(f) (banned devices).

²⁴ 85 Fed. Reg. 11315.

harms, including depression, PTSD, anxiety, fearfulness, suicidality, chronic stress, acute stress disorder, neuropathy, withdrawal, nightmares, flashbacks of panic and rage, and hypervigilance.²⁵ It also found that ESDs may worsen underlying clinical conditions, replacing one negative behavior with another, and result in a loss of agency or “learned helplessness.”²⁶

Second, the FDA concluded that there have been virtually no systematic investigations of the effectiveness of ESDs for self-injurious and/or aggressive behavior.²⁷ Studies that do exist are outdated and methodologically flawed, and many are silent as to any attempts to assess negative side effects.²⁸ Concerns about the accuracy of adverse event reporting were compounded by the age and scientific rigor of the studies themselves.²⁹ No randomized controlled trials were identified

²⁵ 85 Fed. Reg. 13315; *see also*, 81 Fed. Reg. at 24389.

²⁶ 81 Fed. Reg. at 24389.

²⁷ FDA Executive Summary, Neurological Devices Panel (“Panel Summary”) (April 2014) FDA-2016-N-1111-1748 at 44, 58; Table 4: Articles Reviewed for Adverse Events Associated with ESDs for Aversive Conditioning for Patients with SIB and Assaultive/Destructive Behavior associated with Developmental Disabilities at 59-61; <https://bit.ly/3Z4EbBc>; *see also*, 81 Fed. Reg. 24406.

²⁸ Panel Summary at 44, 58.

²⁹ Panel Summary at 58, 64-65. In its Final Rule, the FDA notes that “the only article specifically about JRC’s GED device was published in a peer-reviewed journal over a decade ago, and it studied only nine subjects at JRC (Ref. 7). Studies of ESDs more generally have been published in peer-reviewed journals, but many of them are decades old. In the intervening decades, the understanding of pathophysiology has evolved as has the ability to identify and systematically record AEs. [Adverse Events]. These developments are alongside heightened peer-review standards for study and reporting. Accordingly, it is reasonable to assign these studies less weight than more modern studies.” 85 Fed. Reg. 13319.

by the FDA or its expert panel.³⁰ Articles identified by or presented to the FDA in support of ESDs did not “adhere to current, more exacting peer-review standards for study conduct and reporting.”³¹ The FDA also considered the potential for bias in case studies reporting only ESD benefits and no side effects, including the possibility that some investigators may have been “pre-disposed to see only positive side effects.”³² This potential for bias in overlooking adverse events included the largest case study -- a retrospective review conducted by JRC.³³

Third, the FDA found that there are effective, less restrictive alternatives to electric shock resulting in “durable, long-term benefits” including the reduction or elimination of challenging behaviors.³⁴ The FDA identified a substantial body of peer reviewed literature and empirical research showing that PBS, as well as other evidenced-based treatments and therapies, can reduce and eliminate harmful behaviors through environmental modification and the teaching of adaptive, replacement behaviors. As noted in the FDA’s 2016 proposed rule:

scientific advances have yielded new insights into the organic causes and external (environmental or social) triggers of SIB [self-injurious behaviors]

³⁰ Panel Summary at 57.

³¹ *Id.* at 64-65; 81 Fed. Reg. at 24401 (the majority of articles did not “adhere to current, more exacting peer-review standards for study conduct and reporting.”)

³² Panel Summary at 65 (citing Carr and Lovaas (1981) (“in light of the intrusive nature of shock treatment, it is puzzling that so few negative side effects have been reported.”)).

³³ Panel Summary at 58 (citing Israel et al., 2008).

³⁴ 81 Fed. Reg. at 24410; 85 Fed. Reg. 13315.

and AG [aggressive behaviors], allowing the field to move beyond intrusive punishment techniques such as aversive conditioning with ESDs.³⁵

This evolution in treatment is now well-established: “surveys show the [Applied Behavior Analysis] field as a whole moved away from intrusive physical aversive conditioning techniques such as ESDs 2 decades ago.”³⁶ One FDA Panel expert described this shift by saying:

the Statements of professional programs and the fact of wholesale abandonment of aversive electrical shock therapy professional programs by the peers in this field show that it is unreasonable to conclude that these devices are part of the standard of care for this class of patients

Id.

Put simply, the FDA concluded in its proposed rule, and confirmed in its final 2020 ban, that the risks associated with electric shock are not worth taking:

Although other treatments may not completely reduce or eliminate SIB or AB in all patients, that does not mean ESDs should be used. In determining whether to ban these devices, FDA balances effectiveness against the risks they pose and assesses the reasonableness of such risks in light of the State of the art. The State of the art is to use positive behavioral interventions, sometimes in conjunction with pharmacotherapy, even for the most challenging SIB and AB; the unsubstantiated claim that ESDs are uniquely effective for refractory individuals does not alter that conclusion.³⁷

In sum, the FDA’s compilation of evidence, much of which was presented to and improperly excluded by the Trial Court, provides comprehensive and

³⁵ 81 Fed. Reg. at 24387.

³⁶ 85 Fed. Reg. 13317 (“the professional field, with the sole exception of JRC, has moved beyond the use of ESDs for SIB or AB.”)

³⁷ 81 Fed. Reg. at 24406.

compelling evidence of a significant change in professional standards of care, and a near universal rejection of aversive interventions in favor of safer, more effective treatments. This change in fact justifies termination.

D. The majority of States have limited or prohibited the use of contingent electric shock and other painful aversives.

Recognizing advances in the field, the majority of States have severely limited or banned the aversive techniques being utilized by JRC. As one State legislature concluded:

- (1) Research does not support the long-term efficacy of aversive behavioral intervention;
- (2) The use of aversive or abusive treatment raises disturbing legal and ethical issues, and may well deprive the recipient of constitutional or statutory rights and be outside the ethical guidelines imposed upon the treatment professional;
- (3) Any person with a disability has the same right to be treated with dignity and respect as any other citizen; and
- (4) The use of aversive and abusive treatments on any person with a disability diminishes the dignity and humanity of the treatment professional and the person with a disability.

S. D. Codified Laws § 27B-8-50 (2011).

In 2015 the National Association of State Developmental Disability Directors (NASDDDS) surveyed States about their rules, policies, guidelines, contracts, or practices that governed aversive interventions. Of the 45 States responding, 82% reported that aversives are disallowed for use in service for

people with I/DD.³⁸ The Trial Court was informed of the status of State laws at the time of trial. A more recent search by *amici* has found that at least twenty-eight States have enacted prohibitions against the use of electric shock and other painful aversive procedures.³⁹ The proliferation of State statutes and regulations severely limiting or banning the use of contingent electric shock and other painful aversive techniques, both prior to and after 2018, clearly demonstrates a significant and widespread change in the standard of care for people with disabilities.

E. Policy Statements issued by leading national organizations illustrate the significant change in the standard of care for persons with disabilities.

For years leading up to the trial in this case, professional disability organizations, national associations, and other clinical experts have taken public positions against the use of contingent electric shock. On September 30, 2009, a group of pre-eminent professional and consumer associations for persons with I/DD sent a joint letter to the federal Department of Health and Human Services, the Department of Education, the Attorney General, Congressional Committees,

³⁸ National Association of State Directors of Developmental Disabilities Services, Comment on Proposal to Ban Electrical Stimulation Devices Used to Treat Self-Injurious or Aggressive Behavior, <https://www.nasddds.org/nasddds-offers-comments-to-ban-electrical-stimulation-devices/>.

³⁹ Jurisdictions banning skin shock or other painful aversive techniques include California, Colorado, Illinois, Indiana, Maine, Maryland, Michigan, Missouri, Montana, Nebraska, Nevada, New Mexico, North Carolina, Oklahoma, Pennsylvania, Rhode Island, South Dakota, Tennessee, Texas, Vermont, Virginia, Washington, West Virginia, and Wisconsin.

and Human Rights organizations, calling for an end to “inhumane and unnecessary methods of behavior modification,” including the use of “painful electric shock and food deprivation” at JRC.⁴⁰

In 2010, The Arc of the United States and The American Association of Intellectual and Developmental Disabilities (AAIDD), the oldest and largest interdisciplinary organization of professionals and citizens concerned about the human rights of persons with intellectual and developmental disabilities, issued a joint policy Statement against the use of painful aversives and in favor of positive behavioral supports. *Joint Position Statement of AAIDD and the Arc on Behavioral Supports*, August 23, 2010, extended 2015. In 2019, AAIDD renewed their long-standing call for the “immediate elimination and permanent discontinuation of electric skin shock as an intervention for the behavior of people

⁴⁰ *Letter from Disability Advocates: A Call to Action to Eliminate the Use of Aversive Procedures and Other Inhumane Practices*, to the Dept. of Health and Hum. Serv. et al., (Sept. 30, 2009), <https://mn.gov/mnddc/future/pdf/olmstead/09-ASL-NEW.pdf>. National signatories included the American Association on Intellectual and Developmental Disabilities; the Association of University Centers on Disabilities; The Arc of the United States; the Autism National Committee; The Autistic Self Advocacy Network; the Center on Human Policy, Law, and Disability Studies, Syracuse University; the Disability Rights Education and Defense Fund; the National Association of County Behavioral Health and Developmental Disability Directors; the National Association of Councils on Developmental Disabilities; the National Association for the Dually Diagnosed; the National Disability Rights Network; and the National Leadership Consortium on Developmental Disabilities.

with intellectual and developmental disabilities.” <https://www.aaidd.org/news-policy/policy/position-Statements/electric-shock>.

In 2016, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) which represents State I/DD agencies in 50 jurisdictions, Puerto Rico, and the District of Columbia, submitted formal comments to the FDA, rejecting the use of interventions that cause pain and harm for the purpose of modifying behavior and instead promoting the use of Positive Behavioral Support (PBS). NASDDDS Comments to Ban Electrical Stimulation Devices, <https://www.nasdds.org/nasdds-offers-comments-to-ban-electrical-stimulation-devices/>.

More recently, professional associations specializing in Applied Behavior Analysis have followed suit. The Association of Professional Behavior Analysts (APBA) Board of Directors issued a Statement concluding that contingent electric shock “is generally not the accepted standard of care in the behavior analytic treatment of severe or challenging behavior,” and that its use “goes against the profession’s overarching ethical principles of maximizing benefits for clients, doing no harm, and treating others with compassion, dignity, and respect.” APBA Board of Director Position Statement on the Use of Electric Skin Shock, <https://www.apbahome.net/page/practiceguidelines>.

The Massachusetts Association for Applied Behavior Analysis (MassABA), an organization that represents the interests of behavior analysts in the State, issued

a 2021 position paper stating that contingent electric skin shock is “an unnecessary and demonstrably harmful tactic with possible long-term negative physical and emotional effects,” whose use is “immoral, inhumane, and unethical” and “outside the scope of practice of behavior analysis.” https://www.massaba.net/wp-content/uploads/Position-Statement_Electric-Shock_2021.pdf. Even the Association for Behavior Analysis International (ABAI), which had previously included JRC in its national conferences, recently voted to “strongly oppose the use of contingent electric skin shock (CESS) under any condition.” <https://www.abainternational.org/about-us/policies-and-positions/position-Statement-on-the-use-of-cess-2022.aspx>.

Taken together, these Statements reflect a well-established, emphatic, and widespread rejection of electric shock as a form of behavior modification and constitute compelling evidence of a significant change in fact regarding the standard of care for people with disabilities. They amply support both DDS’ 2011 regulation prohibiting the prospective application of electric shock, and the State’s subsequent motion to terminate the 1987 Consent Decree, underscoring why continued enforcement is inequitable and contrary to the public interest. Finally, these Statements demonstrate that JRC’s reliance on the ABA field to justify the GED is misplaced and ignores changing views within the profession. JRC Brief at 75-77.

IV. Conclusion

For the reasons stated above, the Trial Court's decision should be reversed.

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CERTIFICATE OF SERVICE

I, Steven Schwartz, hereby certify, under the penalties of perjury that on April 3, 2023, I caused a true and accurate copy of the foregoing to be filed via the Massachusetts Odyssey File & Serve site, which also results in service of electronic copies on the registered parties below. Additional courtesy copies were sent by electronic mail to:

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CERTIFICATE OF COMPLIANCE

I, Steven Schwartz, hereby certify that, to the best of my knowledge, the foregoing brief complies with the rules of Court that pertain to the filing of briefs, including but not limited to: Mass. R. A. P. 16(a) (contents of briefs); Mass. R. A. P. 16(e) (references to the record); Mass. R. A. P. 16(f) (reproduction of statutes, rules, regulations); Mass. R. A. P. 16(h) (length of briefs); Mass. R. A. P. 17 (amicus briefs); and Mass. R. A. P. 20 (form of briefs, appendices, and other papers). I also certify that the foregoing brief complies with Mass. R.A.P. 20(a)(2)(C). The brief contains 7,102 non-excluded words in Times New Roman, size 14 font, and was produced using Microsoft Word 2010.

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