

Commonwealth of Massachusetts Massachusetts Developmental Disabilities Council

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Testimony of Lydia Brown To the Joint Committee on Children, Families, and Persons with Disabilities July 14, 2015 H.89 An Act Regarding the Use of Aversive Therapy

Good Afternoon Chairwoman Flanagan, Chairwoman Khan, and Committee Members,

Thank you for giving me the opportunity to address you on H89, "An Act regarding the use of aversive therapy." My name is Lydia Brown and I am a Council Member of the Massachusetts Developmental Disabilities Council. The Council is federally mandated to educate policy makers on both the state and federal level about the intent of legislation and its impact on people with developmental disabilities. In addition, the Council works to improve the system of supports for individuals with developmental disabilities and their families by bringing together lawmakers with advocates to make sure people with developmental disabilities are included in decisions about public policy.

Since 1971, people with intellectual, developmental, psychiatric, and behavioral disabilities have been subjected to painful electric shock, food deprivation, and sensory assault as part of an extremist behavioral modification regimen used at only one institution in the United States. Originally in Rhode Island but relocated in Massachusetts as of 1996, this institution—the Judge Rotenberg Center (JRC)—has always had a large number of placements from Massachusetts. Its supporters will argue today, as they always have, that their children's lives have been saved by aversive behavioral interventions including the electric shock for which it is notorious; however, I urge great caution in substituting large numbers of anecdotal "recovery" stories for scientific evidence borne out of research and practice.

As an autistic person with multiple disabilities working in disability rights advocacy, I am well acquainted with hundreds if not thousands of people with the same disabilities as those who receive these types of aversive interventions at the JRC. Across the country, people with intensive behavioral needs receive effective supports and interventions that do not rely on inflicting pain or fear to change behavior. The people with disabilities receiving aversives of any



(617) 770-7676 (Voice) (617) 770-1987 (Facsimile) www.mass.gov/mddc kind at the JRC are not the only 200-odd people in the country with their behavioral and disability profiles.

You will be told that there is good evidence for the effectiveness and thus acceptability of electric shock aversives; this far-fetched statement is far removed from reality. There is no peer-reviewed research showing any long-term effectiveness from electric shock aversives as a behavioral intervention, except in papers largely self-published by individuals who are closely connected to the one institution that uses it. Twenty-five years ago, several researchers specializing in non-aversive behavior interventions for people with the most challenging aggressive and self-injurious behaviors wrote that:

Clearly, the time has come for limiting the use of stimuli and procedures that are painful, damaging, and dehumanizing. The debate should be not on whether to limit our use of the most severe forms of behavioral intervention, but on how that limitation should occur. [...] The routine use of procedures that deliver pain (shock, pinching, slaps), procedures that result in harm (bruises, cuts, broken bones), and procedures that are disrespectful or dehumanizing (facial sprays, shaving cream in mouth, foul smells) are no longer acceptable.

Ole Ivar Lovaas, the pioneer of electric shock aversives as a treatment for autism, repudiated his work and rejected its use over twenty years ago—in 1993.² Rather than teaching adaptive functioning skills to change or reduce dangerous behaviors, aversive electric shock causes only great suffering, pain, and trauma. At best, the shocks temporarily repress behaviors by using fear as a means of control.

Following a public hearing convened last year, the FDA's neurological devices panel comprised of medical experts found that electric shock aversive devices pose an unreasonable risk of injury, and recommended that they be banned. The previous and current United Nations Special Rapporteurs on Torture have publicly condemned the U.S. in annual human rights reports for taking no action to ban torture in the name of treatment for people with disabilities. Massachusetts outlawed electric shock collars for dogs as cruel and inhumane, but in the absence of a formal ban, it remains not only legally permissible but formally legally sanctioned to electrically shock people with disabilities for punishment.

People with disabilities deserve safe and humane treatment, intervention, and services options that respect inherent human dignity, maximize autonomy, and minimize pain or suffering. For as long as the Commonwealth permits the use of painful aversive interventions on people with disabilities, not only will those currently subjected to such abuses at the JRC continue to suffer, but the state will remain fertile ground for similarly oriented programs or facilities that could expand such methods beyond the one institution where they are currently used.

No words better express the long-lasting trauma caused by painful aversive interventions than those of Ian Cook, a survivor and former JRC resident: "I was in an abusive relationship two

¹ Robert H. Horner, Glen Dunlap, Robert L. Koegel, Edward G. Carr, Wayne Sailor, Jacki Anderson, Richard W. Albin, & Robert E. O'Neill, *Toward a Technology of "Nonaversive" Behavioral Support*, in 30 Res. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 125, 131 (1990).

² Jennifer Gonnerman, School of Shock, Mother Jones, Aug. 20, 2007, available at http://www.motherjones.com/politics/2007/08/school-shock; Dan Moser & Alan Grant, Screams, Slaps, and Love: A Surprising, Shocking Treatment Helps Far-Gone Mental Cripples, in Life MAGAZINE 90-96 (May 7, 1965).

years ago and part of why I fell prey to it is that JRC instilled a lesson in me that it is okay for people to hurt me so long as they are trying to correct me."

In summary, the Massachusetts Developmental Disabilities Council believes that H89 will have a positive impact on people with disabilities if it is passed. We appreciate the opportunity to educate Committee members about the bill and welcome the opportunity to schedule a follow-up meeting with members if additional questions arise.

Sincerely,

Lydia Brown

Council Member The Massachusetts Developmental Disabilities Council