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Comments on the FDA's Proposed Ban of Electrical Stimulation Devices Used to Treat Self-Injurious or Aggressive Behavior

of

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On behalf of the Mental Health Legal Advisors Committee (MHLAC) of the Supreme Judicial Court of Massachusetts, I write to support the FDA's proposed ban on electrical stimulation devices (ESDs) used for aversive behavior modification. MHLAC submitted comments in April 2014 when the FDA initially decided to review the use of these devices. We applaud the FDA's analysis of the Proposed Rule, 81 FR 24385 as detailed and thorough and once again offer our input.

Rather than merely reiterate that ESDs are brutal, ineffective, and supplanted by more humane approaches for addressing problematic behavior, we focus here on a less-cited aspect of the harm wrought by ESDs. That is the harm, which potentially afflicts not only those individuals subject to ESDs, but also those other individuals who witness such events, of being forced to endure the experience. At the Judge Rotenberg Center (JRC), residents suffer these traumatizing events over and over, in insolation from one another and from the larger world. This harm is an appropriate consideration for the FDA in fulfilling its charge to examine all adverse effects of ESDs.

The Proposed Rule well-documents the extensive risks posed by ESDs, including the psychological effects. The Rule also cites NYSED's claim of the potential deleterious effect of the use of ESDs on individuals that witness the use of ESDs on other students:

NYSED states it has received “numerous reports of students who have incurred physical injuries (burns, reddened marks on their skin) as a result of being shocked and for whom parents and students themselves have reported short-term and long-term trauma effects as a result of use of such devices or watching other students being shocked (*e.g.*, loss of hair, loss of appetite, suicidal ideation).”

Rule at II.A.4. This is the precise experience of those at JRC, where residents are routinely present while their fellow residents and students are subjected to the ESD. The effect of observing and hearing other students being shocked cannot be underestimated. It immerses vulnerable residents in a culture of sorrow and fear and, as NYSED explains, contributes to trauma for all students even if they themselves are not shocked.

This harm is compounded by the rules at JRC where certain communications are discouraged and even forbidden. The Proposed Rule speaks of the particular harm of the ESD on individuals who lack the communication skills to express their pain. But the JRC imposes this constraint on all residents by extensively limiting conversations regarding the use of the ESD, creating an environment in which even residents with verbal capacity cannot vent the feelings and seek solace. This exacerbates the trauma of JRC residents. Instead of offering a forum for residents to process their experience, JRC forces them to silently endure.

And endurance is central to the culture of JRC. The Proposed Rule acknowledges that any beneficial impact from ESDs, as opposed to the trauma it causes, will not last absent continued applications of the ESD. Many individuals, therefore, must bear JRC and ESD applications for lengthy periods of time. The Proposed Rule correctly notes that “many students remain subject to ESDs for several years, and many continue to receive shocks long into their adult lives.” Proposed Rule at II.B.3.

The need for ongoing applications of the ESD greatly reduces the potential for community reintegration for those with an ESD. And, we suggest, by creating a culture in which many residents don't progress beyond JRC's doors, JRC compromises its ability to promote this goal of integration for *all* its residents. MHLAC experienced this lack of prioritization of community reintegration when we represented a young woman at JRC who was not receiving shocks. In our advocacy, it was extremely difficult to convince JRC clinical staff to prepare for her return to the larger community. They gave no attention to transition planning and had no sense of urgency regarding discharge. The JRC culture perpetuates the segregation of individuals with disabilities and is in direct contradiction of the integration mandate of the Americans with Disabilities Act.

Instead of preparing residents for a better life, individuals subject to ESD and their observing peers are left to deteriorate, or, as the FDA describes it, to develop “learned helplessness.” One FDA panelist opined that this helplessness contributes to “something analogous to depression.” Proposed Rule at II.A.3. This decline is reminiscent of the mental health asylum of the discredited past – where individuals are squired away and forgotten in a remote location. There, skills and abilities decay as the individual's identity is reduced solely to that of “patient.” It is ironic that JRC touts the ESD as a means to preserve individual access to education and vocational programs when individuals tied to the ESD are, in large part, curtailed

by this apparatus from fully participating in educational and vocational activities outside of JRC. Living in the general community is elusive for those wearing the ESD on their backs.

For the above reasons and all the reasons articulated in the Proposed Rule, MHLAC strongly urges the FDA to enact this measure. In doing so, we further urge the FDA to allow only an extremely brief period, if any, for transition from the use of ESDs to other methods, as discussed in Proposed Rule, at V. While we are generally supportive of careful transitions between treating professionals and programs, we also strongly believe that the immediate provision of positive supports and treatments and the termination of ESD use are the best ways to ensure healing and recovery for those currently subject to the ESD.

Thank you for your consideration.