Oral Comments of the Association of University Centers on Disabilities (AUCD) delivered by Kim Musheno, Director of Public Policy, April 24, 2014

Thank you for the opportunity to comment today. The Association of University Centers on Disabilities (AUCD) is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. Network members consist of:

- 67 University Centers for Excellence in Developmental Disabilities (UCEDD), funded by the Administration on Intellectual and Developmental Disabilities (AIDD)
- 43 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs funded by the Maternal and Child Health Bureau (MCHB)
- 15 Intellectual and Developmental Disability Research Centers (IDDRC), most of which are funded by the National Institute for Child Health and Development (NICHD)

These programs serve and are located in every U.S. state and territory and are all part of universities or medical centers. They serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change.

For many years AUCD has worked in concert with other advocates to ban the use of electric shock and other aversive techniques; AUCD stands with others today to urge the FDA to ban it now and forever. AUCD has also signed on in support of comments submitted by the Alliance to Prevent the Use of Restraints, Aversive Procedures, and Seclusion (APRAIS).

Today, I would like to share comments provided by one of AUCD’s long time Policy Committee leaders, Mark A. Smith, Resource and Family Support Coordinator, Nebraska Center on Disabilities. He wanted to be here today in person but was not able to travel here this week. So, I will read his comments.

Statement of Mark Smith, M.S. on behalf of AUCD

I have worked for over thirty years with individuals with disabilities in a number of roles including direct care provider, behavior therapist, and professional advocate as well as a family member. I currently work as the Family Faculty at a University Center for Excellence in Developmental Disabilities and similarly as part of our Leadership Education in Neurological and other Disabilities training programs. As part of my experience, I participated in returning individuals with intellectual and other developmental disabilities from institutional care to the community. The treatment these individuals received in their institutional placements included painful aversive stimuli. The individuals I worked with who had the capacity to talk about their experiences described situations that were in no way therapeutic or beneficial; they were tortured by staff in mistaken attempts to control aberrant displays of behavior. One need only look at the research on aversive stimuli to note that 1) they act quickly but 2) they are context bound, 3) the problem they were intended to address resumes once the aversive is no longer present, 4) there are data that indicate the individual associates the aversive with the individual administering it, and 5) it can cause situations where the individual displays “learned helplessness” responses, that is they stop responding in any way to avoid the aversive. In fact, the only “treatment” one might associate with painful aversive stimuli is avoidance. One could argue easily that it is in no way treatment in the truest sense of the term.

The information above does not include, from my perspective, the human cost of aversive therapy. Individuals with intellectual and other developmental disabilities are historically a marginalized group within our society. Shuttered away in institutions where in many cases their basic human needs were
(and are) barely met, aversive therapy exacerbates a dehumanizing environment, further indicating to the individual that they are “less than” those who are implementing aversive treatment, leading to conditions where these individuals are seen as less than human. In my experience of returning individuals to community living, I worked with dozens if not hundreds of individuals with extremely challenging behavior, including life-threatening self-injury, high rates of aggression, and property destruction. Aversive treatment was never employed in any of these cases, yet an overwhelming majority of these individuals not only remained but thrived in community placements through persistent, positive approaches to addressing their behavior. We found that the more the individual could assume appropriate control over their lives in addition to effectively communicating, the less interfering problems were observed.

In my work, I have noted that there remain proponents of aversive therapy, in particular electric shock. Based on my comments above, this is literally perplexing to me. It is not treatment (in fact I would consider it torture) and is unnecessary and should be banned as an approach to treating severe behavior, period. I make this statement based on my experience as well as my educational and professional training. It is time to include individuals with disabilities as participating members of our communities while providing support where needed, including behavioral and mental health supports. This need not and should not include electric shock aversive therapy. It is well past time to move beyond antiquated and destructive approaches when it comes to citizens of this country regardless of condition.

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Therefore, on behalf of Mark and the entire AUCD network, I urge this committee to advise the FDA to ban the use of Electrical Stimulation Devices (ESDs) for aversive conditioning. ESDs present a substantial and unreasonable risk of abuse and injury. Substantial research and evidence on the use of alternative positive behavioral supports and interventions and successful de-escalation techniques make these devices outdated and completely unnecessary.

Please feel free to contact me or Mark at AUCD for additional questions or for referral to other experts in our network on this topic.

Thank you.

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