



Department of Health and Social Services

GOVERNOR'S COUNCIL ON DISABILITIES & SPECIAL EDUCATION Patrick Reinhart, Executive Director

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RE: Proposal to Ban Electrical Stimulation Devices Used To Treat Self-Injurious or Aggressive Behavior (Docket No. FDA-2016-N-1111)

The Alaska Governor's Council on Disabilities and Special Education fills a variety of federal and state roles, including serving as the State Council on Developmental Disabilities (SCDD) under the Developmental Disabilities Assistance and Bill of Rights Act. As the Alaska DD Council, we work with state and federal agencies to ensure that people with intellectual and developmental disabilities and their families receive the services and supports that they need, as well as participate in the planning and design of those services. One of the duties of the Alaska DD Council is providing comments on proposed recommendations that may have an impact on individuals with intellectual and/or developmental disabilities and their families.

The Alaska Governor's Council strongly supports the Food and Drug Administration's (FDA) proposed rule to ban the use of electrical stimulation devices (ESDs) for treating self-injurious and aggressive behaviors. As an advisory and advocacy organization, we have long been in opposition to the use of physically coercive means to treat challenging behaviors. It is clear to the members of the Alaska Governor's Council that the use of an ESD can result in long-term psychological harm, which undermines a person's ability to live as a valued member of society.

The United Nations Special Report on Torture, scientific research, and the FDA itself has determined that these devices present an unreasonable and substantial risk of illness or injury without long-term benefits to the individual. Current evidence-based best-practices for addressing challenging behaviors are positive rather than punitive behavioral approaches, and do not include the use of ESDs.

Individuals with aggressive behaviors have a *primary disability* that has an impact on their intellect and communication; the aggressive behavior is the *secondary disability* to this basic struggle to communicate their needs and wishes with others. The use of punitive punishment on this, our most vulnerable, population does nothing to teach effective communication or to enhance the individual's ability to make their needs known in an appropriate manner. Instead, ESDs present a painful roadblock to this most basic of human needs. The use of positive strategies allows individuals to learn that communication is an effective way to get their needs

met and enables them to learn to manage their own behaviors. We therefore support the FDA's ban on the use of these harmful devices.

Sincerely,

Alm

Amy Simpson, Chair Alaska Governor's Council on Disabilities & Special Education

Jenne Gerlandt-Gymo

Jeanne Gerhardt-Cyrus, Chair Developmental Disabilities Committee Fetal Alcohol Spectrum Disorders Workgroup