DRAFT IACC LETTER ON SECLUSION AND RESTRAINT July 2011

The Honorable Kathleen Sebelius Secretary
U.S. Dept. of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Dear Madam Secretary,

The Interagency Autism Coordinating Committee (IACC) is interested in and concerned about several important health and safety matters that affect people with Autism Spectrum Disorders (ASD). One principal concern relates to the inappropriate use of seclusion and restraint in a variety of settings that receive federal funding, including institutional facilities such as hospitals and residential treatment facilities for children, schools, prisons, and home and community-based settings.

Over the past fifteen years, media attention and the advocacy of the disability community has resulted in questions about efficacy and appropriateness of these practices. Just a few weeks ago, the *New York Times* ran a front-page article about the death of a youth with developmental disabilities as he was restrained by staff. Stories like this abound. During the period April 2010-January 2011, one non-profit organization identified over 50 media stories highlighting the use of seclusion or restraint on children.

The Government Accountability Office (GAO) has issued multiple reports related to seclusion and restraint since 1999, with the most recent in 2009 focusing on children and youth in educational and behavioral health treatment settings. Although some progress has been made in recent years due to Congressional, federal, and state efforts to eliminate and reduce seclusion and restraint, the IACC believes further steps can be taken by the Department of Health and Human Services (HHS) to help assure the safety of vulnerable citizens subjected to involuntary confinement and restrictions on movement.

According to the Substance Abuse and Mental Health Services Administration (SAMHSA), each year approximately 150 people die as a result of seclusion and restraint practices, and countless others are injured or traumatized. The GAO reports that tens of thousands of seclusion or restraint incidents take place in our schools annually. Yet there is very little reliable data to describe the full extent of the problem and inconsistent laws, regulations and standards across settings have subjected people with ASD and related disabilities to the use of these dangerous and demeaning practices.

Utilization of restraint or seclusion should be viewed as a treatment failure that exacerbates behavioral challenges and induces additional trauma. Restraint and seclusion have no demonstrated therapeutic value. The Cochrane Collaboration, which systematically reviews health care practices, has observed that “few other forms of treatment…are so lacking in basic

information about their proper use and efficacy." These are emergency interventions that should only be used when the danger of harm to self or others clearly requires such invasive techniques, and only when staff have been trained in alternatives as well the appropriate emergency use of these techniques. Alternative approaches and practices such as Positive Behavior Supports have been shown to significantly reduce the use of restraint and seclusion in both treatment and educational settings.

At a joint meeting of the Services and the Safety Subcommittees of the IACC on May 19, 2011 national experts including federal staff, stakeholders and advocates shared information about efforts to reduce and eliminate seclusion and restraint. As a result of these discussions, we would like to recommend your consideration of the following action items:

Promulgate regulations: Two sections of the Children's Health Act of 2000 (Act) **[need cites]** fully support regulation of restraint and seclusion, yet only an interim final rule has been published. The Centers for Medicare & Medicaid Services (CMS) should issue a final rule on the use of these interventions in Psychiatric Residential Treatment Facilities (PRTFs) for children under the age of 21. Additionally, the Act provides for regulation of restraint and seclusion in "non-medical, community-based facilities for children and youth" receiving federal funds. SAMHSA and CMS should immediately begin to work together to issue a rule in collaboration with the Department of Education to address seclusion and restraint across settings that are presently regulated only through an insufficient patchwork of State and local regulations. HHS should also explore the use of Section 2402(a) of the Affordable Care Act, which addresses the removal of barriers to providing home and community-based services, as another means to achieve consistent policies for seclusion and restraint across programs.

Improve data collection across settings: Federal agencies including SAMHSA, CMS, the Administration for Children and Families (ACF), the Department of Justice (DoJ), and the Department of Education (ED) should work together to identify opportunities to improve data collection and reporting of seclusion and restraint incidents. Improved data is imperative to understand how many people are at risk, where seclusion and restraint is happening, the circumstances involved, antecedent behaviors, potential causes, staff training needs, and effective preventive supports and interventions.

Develop collaborative guidance: HHS, ED, the DoJ and other relevant Federal agencies need to work together to provide additional guidance and technical assistance to schools, service providers, criminal justice workers, health professionals and families about best practices and alternatives to restraint and seclusion, as well as the dangers related to these interventions.

Bring attention to the issue: HHS should convene a national interagency conference or summit on seclusion and restraint with ED and the DoJ, to highlight alternatives and best practices, including the use of Positive Behavior Supports and SAMHSA's Six Core Strategies to Reduce the Use of Seclusion and Restraint. Such a national dialogue will focus efforts on policy consistency across jurisdictions and settings.

Reduce or eliminate the use of seclusion and restraint in schools: Given the current lack of federal authority to regulate these interventions in educational settings, legislation is urgently needed to ensure the safety of all students and staff. Members of the IACC support federal

legislation that would require States to establish minimum standards for schools; establishment of monitoring, enforcement, and reporting rules; prohibition of the use of any mechanical restraint, chemical restraint, or physical restraint that restricts breathing and aversive behavioral interventions that compromise health and safety; limiting the use of physical restraint or seclusion to circumstances when there is imminent danger of injury; and requiring that seclusion and restraint only be imposed by trained staff.

The use of seclusion and restraint in every setting is a critical issue for people with ASD and other disabilities and their families that requires immediate federal attention. We greatly appreciate your consideration of our concerns and look forward to your response.

Sincerely,