DRAFT IACC LETTER ON SECLUSION AND RESTRAINT
September 7, 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. This summer, the *New York Times* ran a front-page article about the death of Jonathan Carey, a thirteen year old boy with non-verbal autism who was asphyxiated when a State employee sat on him while trying to subdue him in the back of a van.[1] Stories like this abound, such as the death of a seven-year old girl who was suffocated after being restrained for blowing bubbles in her milk, and another boy killed in a restraint used to prevent him from leaving a classroom. One non-profit organization identified over 50 media stories highlighting the use of seclusion or restraint on children during the period April 2010-January 2011.[2] Survey data and anecdotal reports indicate that the majority of the children involved are under the age of 12.[3, 4]

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

[1] Hakim, Danny. "A Disabled Boy's Death, and a System in Disarray." New York Times on the Web June 5, 2011. http://www.nytimes.com/2011/06/06/nyregion/boys-death-highlights-crisis-in-homes-for-disabled.html?pagewanted=all
[2] The Cost of Waiting: A Report on Restraint, Seclusion and Aversive Procedures. TASH, April 2011. http://tash.org/wp-content/uploads/2011/04/TASH_The-Cost-of-Waiting_April-2011.pdf
[3] Unsafe in the Schoolhouse: Abuse of Children with Disabilities. Council of Parent Attorneys and Advocates, May 27, 2009. http://www.copaa.org/wp-content/uploads/2010/10/UnsafeCOPAAMay_27_2009.pdf.
[4] NRI Performance Measurement System. *National Public Rates, Age Stratification Report: Restraint Hours.* Alexandria, VA: National Association of State Mental Health Program Directors Research Institute, Inc., February, 2008. http://www.nri-inc.org/reports_pubs/2008/public_age_stratification_rates_feb2008.pdf

educational and behavioral health treatment settings.[5] Congressional hearings in 2008 and 2009 examined the abusive and deadly misuse of seclusion and restraint of teens in residential treatment programs and schools. 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 children and adults subjected to these behavioral interventions involving involuntary confinement and restrictions on movement that can put individuals at risk of emotional trauma, injury, or death.

According to an expert from the Harvard Center for Risk Analysis, each year approximately 50-150 people die as a result of seclusion and restraint practices, and countless others are injured or traumatized.[6] The GAO reports that tens of thousands of seclusion or restraint incidents take place in our schools annually.[7] 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. Recent research indicates that contrary to what was previously thought about these practices, there is very little evidence to indicate that seclusion and restraint practices hold therapeutic value.[8] The Cochrane Collaboration, which systematically reviews health care practices, concludes that "in the absence of any controlled trials in those with serious mental illness, no recommendation can be made about the effectiveness, benefit or harmfulness of seclusion or restraint."[9] 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 as the appropriate emergency use of these techniques. Alternative approaches and practices such as Positive Behavioral Interventions and Supports (PBIS) have been shown to significantly reduce the use of restraint and seclusion in both treatment and educational settings.[10, 11, 12, 13]

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[5] United States Government Accountability Office: Testimony Before the Committee on Education and Labor, House of Representatives. Seclusions and Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers. Statement of Gregory D. Kutz, Managing Director Forensic Audits and Special Investigations. http://www.gao.gov/new.items/d09719t.pdf.

[6] Weiss, E.M., Altimari, D., Blint, D.F., & Megan, K. (1998, October 11-15). Deadly restraint: A nationwide pattern of death. *Hartford Courant.*

[7] United States Government Accountability Office: Testimony Before the Committee on Education and Labor, House of Representatives. Seclusions and Restraints: Selected Cases of Death and Abuse at Public and Private Schools and Treatment Centers. Statement of Gregory D. Kutz, Managing Director Forensic Audits and Special Investigations. http://www.gao.gov/new.items/d09719t.pdf.

[8] Mohr W, Anderson JA. (2001). Faulty assumptions associated with the use of restraints with children. *Journal of Child and Adolescent Psychiatric Nursing, 14*(3), 141–15. http://www.ncbi.nlm.nih.gov/pubmed/11814080

[9] Sailas EES, Fenton M. Seclusion and restraint for people with serious mental illnesses. *Cochrane Database of Systematic Reviews* 2000, Issue 1. Art. No.: CD001163. http://www2.cochrane.org/reviews/en/ab001163.html

[10] Smith GM, Davis RH, Bixler EO, Lin H-M, Altenor A, Altenor RJ, Hardentstine BD, Kopchick GA. Special Section on Seclusion and Restraint: Pennsylvania State Hospital System's Seclusion and

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, the committee would like to recommend your consideration of the following action items:

Promulgate regulations: Two sections of the Children's Health Act of 2000, Part H and Part I, 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. The Substance Abuse and Mental Health Services Administration (SAMHSA) and CMS should immediately begin to work together to issue a rule 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. HHS efforts should be coordinated with efforts in the Department of Education (ED) on the issue of seclusion and restraint to ensure consistency across agencies.

Improve data collection across settings: Federal agencies including SAMHSA, CMS, the Administration for Children and Families (ACF), the Department of Justice (DoJ), and ED should coordinate efforts to identify opportunities to improve data collection and reporting of all seclusion and restraint incidents, including the evaluation of such data regarding outcomes and the impact of the use of these interventions. The Department of Education's Office for Civil Rights initiated significant restraint and seclusion data collection requirements in 2009-10 for public schools through their annual *Civil Rights Data Collection Survey;* the first reported data is expected to be available later this year. Current data in many other settings only identify circumstances involving death or serious injury; the Committee feels it is critical to have consistent incident data collected in all instances when restraint or seclusion practices are used and across settings to the greatest extent possible. Improved data is imperative to understand how many people are at risk, where seclusion and restraint is happening, the circumstances

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Restraint Reduction Program. *Psychiatric Services.* 2005 56: 1115-1122. http://ps.psychiatryonline.org/cgi/content/abstract/56/9/1115

[11] Learning From Each Other: Success Stories and Ideas for Reducing Restraint/Seclusion in Behavioral Health. American Psychiatric Association, American Psychiatric Nurses Association, and the National Association of Psychiatric Health Systems. 2003. http://www.naphs.org/rscampaign/learning.pdf

[12] Miller, D.N., George, M.P., & Fogt, J.B. (2005). Establishing and sustaining research-based practices at Centennial School: A descriptive case study of systemic change. Psychology in the Schools, 42, 553–567. http://www.lehigh.edu/~insch/article_5.pdf

[13] George, M. P., White, G. P. and Schlaffer, J. J. (2007), Implementing school-wide behavior change: Lessons from the field. Psychology in the Schools, 44: 41–51. http://flpbs.fmhi.usf.edu/revision07/research/Research%20Articles%20Supporting%20PBS/implementingswpbslessons.pdf

involved, antecedent behaviors, potential causes, staff training needs, and effective preventive supports and interventions.

Develop collaborative guidance and technical assistance across agencies: HHS, ED, the DoJ, and other relevant Federal agencies need to coordinate with each other in their efforts 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. The Committee would like to encourage strong collaboration across agencies and additional investment of resources in order to improve the dissemination of information, research, and tools to help families, providers, and the broader community to access and implement best practices, such as PBIS across a variety of settings.

Bring attention to the issue: HHS should convene a national interagency conference or summit on seclusion and restraint, in collaboration with ED and the DoJ, to highlight alternatives and best practices, including the use of PBIS 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; establish monitoring, enforcement, and reporting rules; prohibit the use of any mechanical restraint, chemical restraint, or physical restraint that restricts breathing and aversive behavioral interventions that compromise health and safety; limit the use of physical restraint or seclusion to circumstances when there is imminent danger of injury; require that seclusion and restraint only be imposed by trained staff; and ensure that family members are immediately notified of each seclusion and restraint incident.

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,