

Testimony to the Senate Education Committee
Testimony in Support of HB 2444 – Freedom from Unsafe Restraint & Seclusion
Act

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I am a parent of a 10 year old boy named Jonathan (Jon) with severe autism. Jon is nonverbal, communicates primarily with sign language. He is one of the most challenging students.

I volunteer as a supporting parent for Families Together. Many of the parents I provide support to are referred to me because of their child's problem behaviors and resulting issues with school districts. I also help lead a local support group for families with Developmental Disorders. I hear from other parents that some school districts are still using Seclusion and Restraint as a behavior managing tool and not just to prevent harm to self or others. While administrators work to convince parents that Seclusion & Restraint is necessary and should be part of the IEP, they do not want to admit to the outside world that such procedures are being used. They have secret padded rooms and resist providing parents with written policies. When problem behaviors escalate and parents begin questioning, school districts limit parent's access to information and to staff.

In 2007 when Jon was 5 years old, I was told that staff would not use a "safe room" without discussing it with me and Seclusion and Restraint was not needed at this time. However, notes that came home from school indicated that my son was put in another room, in the "time away area". At this time I was very trusting and did not follow up on these notes. I was unaware that there was a seclusion room in the school building until a year and half later when I heard from another parent that their son had been put in a seclusion room in that same school without her knowledge or consent. During this time period Jon's aggressive and self-injurious behavior escalated from an occasional incidence to multiple times per day. In Spring 2007 he started coming home with red bite marks on his hands and soon developed raised red, cracked calluses on both hands from biting himself multiple times per day. Jon's personality changed from being a very happy kid to being very frustrated and angry. We tried repeatedly to get the school district to bring in an outside expert to help but they insisted that they knew what they were doing. Finally in March 2008 we filed for a Due Process Hearing and we are still in the appeal process waiting for a judge's decision. From this experience we learned

that IDEA and the Kansas State statutes have very limited laws that govern how schools handle behavior problems. Without laws parents cannot hope to prevail in Due Process proceedings. In July 2008 we took Jon out of the public school and put him in the Kansas City Autism Training Center, where they managed his behaviors with appropriate Positive Behavioral Interventions and Supports with proactive and reactive procedures. Jon attended the KCATC for two years and we spent \$100,000 to get his behaviors under control and provide him with programming that gave him more independence and spontaneous communication. He became a happy kid again.

In the efforts to help Jon I learned a great deal about Positive Behavior Interventions and Supports from Autism and Behavior experts. I am now very passionate about educating other parents to help them negotiate with IEP teams to get appropriate goals and services. Educated parents will help to limit the use of Seclusion and Restraint procedures, but we need your help. Anytime such procedures are used there is the potential for abuse and harm. We need laws to keep that from happening. These students have IEPs, Individualized Education Plans. Seclusion and Restraint procedures are a “one size fits all” approach and the individual needs of the student are being ignored. Seclusion and Restraint can reinforce and actually escalate the behaviors that they are trying to stop and damage the already fragile emotional wellbeing of our kids.

Positive Behavioral Interventions and Supports will use a Functional Behavioral Analysis to determine why these kids do what they do, find replacement behaviors so that they do not have to use these behaviors to get what they need, determine problem areas in the environment, a task analysis of the skills to determine the education methodologies that would enable the student to learn more and reduce the frustration which in turn will help to reduce the behaviors. These students, like Jon, have such difficulties in communication, can be taught a functional, spontaneous, independent form of communication that will help reduce their need to use their severe behavior as communication. PBIS can be determined for students with the potential for severe behaviors to prevent rather than to stop these behaviors. We shouldn't wait to “put out the fires” but keep the behavioral “fires” from even starting.

Using Positive Behavioral Interventions and Supports and being proactive will provide the best possible outcomes for students like Jon, in the long term save money and time for the school district and likely save the State money by keeping

kids from being institutionalized because of behaviors, and keep parents from going broke to save their kids to keep them part of the family.

You can help by making these nonbinding guidelines on Seclusion and Restraint into law to keep these damaging procedures from being abused and give hope to parents like myself. By doing this YOU can help protect Jon and children like him and give us hope for a brighter future.