Testimony in Support of Substitute HB 2170 By Tonia Wade

Hello Mr. Chairman and members of the Committee. My name is Tonia A. Wade. I am the parent of a beautiful 16-year-old child with a disability. My daughter Kaliya has profound Autism and attends school in Kansas City Kansas.

The current regulations on the use of restraint and seclusion fail to protect Kansas children. Passing this bill will fix that problem. So you know, I and many other parents have testified to the State Board of Education over the last two years pointing out these flaws in their regulations. The flaws have still not been addressed – two years later. We have given them long enough to fix this. In total, parents have been waiting 10 years for an effective policy. The Senate has deferred action on this issue twice over the last ten years. We would not be here today if effective action was taken before. How many more Kaliya's or lan's or Mick's or other kids must suffer before we act to create an effective policy. I pray that you will hear my story and support this bill.

I found out in one of the worst ways possible that my Kaliya was being harmed by being forced into seclusion. Prior to this incident, I did not even know this was happening to my child.

Kaliya was forced against her free will into a scary and tiny box that the school was using as a seclusion room. It was a small makeshift box built out material you can get at your local hardware store. This box looked more fitting for a dog than a child. As I recall, it was only around three foot wide and too small for an adult, let alone a child, to safely fit inside.

Kaliya was forced against her will into this glorified box and it traumatized her. I was called to the school because of how Kaliya was "reacting" to being forced into the box. When I saw Kaliya, I was stunned. When I came to her rescue, my daughter was lying naked on a cold, hard floor. She was so traumatized by the box that she had taken off all her clothes. Her pupils were dilated. She kept repeating "Mommy no breath," which is her way of saying she was so traumatized that she could not breathe. She

was crying, sweating and trembling. She was so traumatized that I had to take her to the Emergency Room at the KU Med Center.

That experience forever scarred my daughter. Since being forced into seclusion she has had terrible anxiety with physical repercussions. She can't sleep by herself. She was potty trained years before being forced into the box. She now defecates on herself. She is of course afraid of the dark and enclosed spaces. She is now broken. No child should have to go through what Kaliya went through. That is where you come in. You have the power to fix this.

Even though this incident occurred seven years ago prior to the current regulations going into effect, what happened to my daughter is still incredibly relevant to this bill. Scary, tiny, terrible boxes like the one Kaliya was forced into are STILL ALLOWED under the current regulations. This bill would prevent that. The current regulations STILL have an UNCLEAR standard of when it is allowable to use seclusion or restraint, ensuring children will be subjected to these dangerous measures inappropriately. This bill fixes that. The so-called proposed "appeals process" from the State Board treats parents unfairly and differently from schools. This bill addresses that by ensuring an independent complaint process where parents are treated "equally."

Because of my advocacy, the school <u>dismantled</u> the box years ago. Now, we need to work together to <u>build up</u> the right policy to prevent future tragedies.

Mr. Chairman, I want to personally thank you for your leadership on this important issue. As I recall, back in 2006 you were the Chairman of the State Board of Education. Under your leadership, Mr. Chairman, the State Board came very close to passing regulations much like the bill before you today. That proposal was an excellent policy. It was actually a little stronger than this bill. It was written under your leadership and by your staff. What I want the Committee to know is this. If that proposal would have passed back then, my Kaliya would have NEVER been forced into that scary, tiny, terrible box. Let me repeat that, because it is important. If that proposal would have passed into law at that time, my Kaliya would not

be broken today. Your proposal back then, Mr. Chairman, would have established the right protections to ensure that restraint and seclusion only be used if there is danger of substantial physical injury to self or others. It would have kept my Kaliya and other Kansas kids safe. We must learn from the past and prevent future tragedies. Thank you, Mr. Chairman, for your leadership to try to fix this problem.

Finally, the bill incorporates the U.S. Department of Education recommended standard regarding when restraint and seclusion can be used. That is a critical protection in this bill. The current regulation fails to keep Kansas kids safe because it uses an unclear standard of "danger to self or others." The current standard simply says "danger." Danger of what? The regulations do not say. A danger of rocking back and forth? A danger of appearing defiant? Due to her profound Autism, my daughter rocks back and forth. She repeats back what others say. That can be misinterpreted by others as being threatening and defiant. She's not. It's just part of her disability. Under the current definition she could be secluded or restrained because she was a "danger" of being obstinate and defiant. The current regulation just says "danger." Again, danger of what? It does not say. The bill makes clear that it the US Department of Education standard be used, which is "danger of serious physical harm to self or others." Without that standard, Kansas kids will continue to be subjected to restraint and seclusion inappropriately.

We can't go back in time. We can't go back and undo what happened to my daughter. I pray every day that I could go back in time, but I can't. We can't undo the harm that has happened to children under the current regulations – like Ian and Mick. However, we can learn from the past and fix this policy so that the harm stops here and now. Please do not wait any longer. We have all waited long enough. Thank you. I will answer questions at the appropriate time.