

Testimony before the Select Committee on Children

March 6, 2012

Regarding

HB 5347- AN ACT CONCERNING THE REPORTING OF CHILDREN PLACED IN SECLUSION

Senator Gerratana, Representative Urban and members of the Select Committee on Children: My name is Christine Rowan. I am a Connecticut resident and the mother of three young daughters. My oldest daughter, Amanda, is autistic and struggles with behavioral challenges typical of autism.

I am here today, on behalf of Amanda, our family and, as part of the Keep the Promise Children's Committee, other children of Connecticut, to ensure success in school for all kids, especially the ones who may present more of a challenge through behavioral or mental health issues. I would like to thank the Committee for raising a bill to address the reporting requirements of children placed in seclusion as I am all too aware that seclusion is being improperly utilized.

While enactment of HB 5347 would ensure effective monitoring of restraint and seclusion in schools, my concern is that this bill does not address the underlying issue at hand: **the use of seclusion in schools**. Under the current law, the use of seclusion may be written into a child's IEP (individual education plan) as a method of intervention. The use of seclusion as an educational tool is ineffective, dangerous, frightening, humiliating and degrading. Used in this way, seclusion allows schools to forego more positive and effective interventions.

In order to protect the children of Connecticut and in order for them to succeed in school, seclusion must be limited to emergency use only and NEVER as an educational tool which can be written into a child's IEP. Monitoring and reporting accountability must be improved as well. Unfortunately, I learned all this through personal experience.

Our seclusion nightmare began during the 2007/2008 school year, when my daughter, Amanda, was attending first grade in Connecticut public school. At just **seven years old**, over a seven month period of time, Amanda spent over **forty (40) hours** of seclusion in a small cinderblock time-out room—several minutes to one hour at a time per incident and sometimes up to several hours per day collectively. The use of seclusion had made its way into Amanda's IEP.

Amanda has limited speech and ability to express herself. She suffers from anxiety and sensory issues. She has poor balance and extremely poor fine motor skills. At the time, she was quite sickly, suffering from severe skin rashes of unknown origin and several bouts of strep throat. Although Amanda was happy a lot of the time and enjoyed her classmates, she also had great difficulties with transitions, dropping to the floor, crying and whining. These same behavioral challenges had been going on through Amanda's prior 4 years in public school as well – 3 years of preschool and 1 year of kindergarten.

Amanda's teachers and therapists really adored her and tried to help her, but they didn't have the training, tools and interventions available to them to properly address her needs. At the recommendation of several independent evaluators, I began requesting additional interventions to help Amanda: an AAC (assistive/augmentative communication) evaluation to help my daughter communicate especially when frustrated or upset; an AT (assistive technology) evaluation to address



my daughter's severe fine motor problems and thus reduce frustration by making the work more accessible for her; ABA programming with staff trained in working with autistic children; and the help of a BCBA (Board Certified Behavior Analyst).

All but one of the interventions I requested were denied. The district agreed to assign one of their Board Certified Behavior Analyst's to Amanda's case. Initially, a "cool down" procedure was described to my husband and I – whereby Amanda would be brought to a bean bag chair in the resource room where she could calm down and then return to her work. We readily agreed to this procedure. After our next PPT meeting, however, the time-out/seclusion language appeared in Amanda's IEP as part of her educational programming. Nobody explained our legal rights with regard to seclusion or that the language was being put into the IEP. ***My husband and I may have agreed to try time-out, but nobody showed us the seclusion room to be used or explained to us the kind of open ended time-out they were planning. At the time, I was completely unaware of the laws governing seclusion and restraint in schools.***

Amanda would be exhausted after a long stint in the seclusion room. Thus, she was unavailable for learning both during and after these traumatic time-outs occurred. Other more positive behavioral interventions could have made learning more enjoyable for Amanda and reduce behavioral challenges, including lessen her frustration. As I said, some time-outs lasted up to an hour at one time. Amanda never had tantrums at school lasting anywhere near that time prior to the implementation of the seclusion program. ***Seclusion actually escalated Amanda's tantrums instead of diffusing them.*** One of Amanda's aide's once told me that she didn't think Amanda understood how to get out of the seclusion/time-out room. There were no visuals to remind her she needed to count down and say she was "ready" to get out. ***Observing from the window in the door, the aide would see Amanda calm down, look around confused and then get agitated all over again.***

Once the long periods of seclusion began, I felt powerless to stop it. I felt it was my fault – triggered by my attempt to advocate for my daughter. After days turned into weeks turned into months, I met with the behavior analyst and asked her to please revise her plan – obviously after months of use, the seclusion wasn't working. She disagreed and showed us lots of charts and data to suggest it was working. The time-out continued. Again, I asked the behavior analyst to stop using the time-out or at least develop a phase out plan and give me an end date. At the next PPT meeting, she said "I considered your request, and the answer is no." The time-out continued.

The behavior analyst working with Amanda truly believed she was helping her. She did not intend to hurt my daughter. ***But one person's idea of effective behavior intervention can be another person's nightmare. That is why it is up to the legislation to draw the line. Seclusion should not be left to the discretion of individuals to use as an intervention.*** If I locked my daughter in a closet at home for up to an hour at a time for months on end – it would be considered abuse. Yet, this law allows schools to do just that.

Amanda's long term aide quit shortly after the implementation of the time-out program. I thought it was because she didn't want to deal with Amanda's challenges anymore. I later found out it was



because she disagreed with the cruel use of seclusion and refused to implement it. She loved my daughter and tried to protect her.

Finally, we made the difficult decision to pull Amanda from the school and classmates she loved and unilaterally place her in a private special education school. We did this primarily because Amanda's safety became our first priority. However, I believe Amanda could have remained in the public schools with the proper interventions. Seclusion actually denied Amanda her right to be safely educated in the least restrictive environment.

I am certain that what happened to my daughter is not an isolated incident. After hearing about the children in Middletown, I decided I must tell our story to keep this from happening to more kids. Don't be fooled into thinking the Middletown problem was an isolated situation either. Those kids just got lucky because one brave parent spoke up to the right person and set off a domino effect of parent complaints. I also found out later that many of Amanda's typical peers and their parents were distraught at how Amanda was being treated. But parents often keep silent because they don't want to interfere; or they do complain but their concerns go unaddressed. Connecticut children in other schools shouldn't have to rely on that one brave parent reaching the right person to protect them. The law should protect them.

The stress of our personal experience with seclusion took a tremendous toll on Amanda and my entire family. The main thing that got me through was my faith and trust that God can work all things for good.

I implore you, let this be the good to come out of a horrible situation. Protect the children of Connecticut. Limit seclusion to emergency use only and improve monitoring and reporting accountability of both restraints and seclusions.

Thank you for your attention.



