

January 31, 2012

To the Children and Families Committee,

I am a parent of a 10 year old boy with severe autism. He is nonverbal, communicates primarily with sign language. I also 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.

In January 2007 I first became aware that Seclusion and Restraint procedures were being used in schools to control problem behaviors. During an IEP meeting on January 26, 2007 I questioned the IEP team about these procedures and according to the recorded minutes of the meeting "Assured Mom, (my son's name) would not use safe room w/o discussion. Not needed at this time." However, notes that came home from school indicated on January 26, 2007 and February 2, 2007, March 14, 2007 that my son was put in a bean bag chair in another room, in the "time away area". At this time I was very trusting of the school district and did not follow up on these notes. I was really unaware that there even 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. I have no other proof that he was put in a seclusion room. During this time period my son'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,

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FAMILIES  
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cracked calluses on both hands from biting himself multiple times per day. His personality changed from being a very happy kid to frequently becoming 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. In July 2008 we took our son 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. Our son 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 May 2011 I wrote the following essay that addresses just some of the damage seclusion and restraint procedures have on students and their families.

#### ISOLATED

Several days ago I forwarded an email to our support group from TASH entitled "Shouldn't-School-Be-Safe, regarding information on Seclusion and Restraint. What should be included in the policies and guidelines, what to look for to determine whether these procedures are being used on your child with out your consent. I passed the info on as a FYI and was almost apologetic and not wanting anyone to think that I felt that Seclusion and Restraint was a problem in our school district. I stated that schools are permitted to use these procedures when a student is exhibiting aggressive behaviors to

prevent physical harm to self or to others, to include damaging property, since in doing so could harm self or others. I also stated that it was documented that our school district had used these procedures in the past. I also stated that anytime procedures like this are being used there is the potential for abuse or misuse for reasons other than prevention of physical harm and in the place of appropriate **Positive Behavior Interventions and Supports**. Soon after sending this FYI email I received an email from a parent in our support group telling me that school staff where her child attended were inappropriately using these procedures in response to her child's behaviors that were not posing imminent danger of physical harm to self or others. I hate to admit it but I was somewhat shocked by this revelation. I really thought the problems in past had educated this school district and we would not have to worry about it any more. I should have known better. When this parent told me that she had not been able to get the school staff to provide her with the District's Policy on Seclusion and Restraint I promptly sent an email to the Special Education Administration of our school district requesting the policy on behalf of our support group. I felt that everyone had the right to see it and should, if for no other reason, be proactive and read it. I saw nothing wrong with my request and saw it as necessary. Shortly afterwards I received an email from another member of our support group telling me they believed I should be more careful sending such emails on behalf of the group, that it would look like we were ganging up on the school district and would damage our relationship with the district. After all there is just an **isolated** few who will have to deal with this issue. It would be better to just request the policy on behalf of a parent or have the parents who need to know about it, request the policies themselves.

Here is my response to that kind of thinking. The key word here is ISOLATED. Yes, there are just a few of us that have to deal with the types of behaviors for which school districts find themselves using Seclusion & Restraint. This kind of thinking just isolates us that much more. Our children are ISOLATED because of the severity of their disorder. They are ISOLATED because of the behaviors that hurt self or others. Have you ever watched a child repeatedly self injure in frustration, anger, or for the physical sensations they get? It is very disturbing. It immediately stigmatizes them, labels them and further isolates them from their peers and anyone who is unfortunate to be around them. No one wants to see that, to be around that, to live with that. Have you ever been around a child that is aggressive and has learned to get any reaction, positive or negative, to their behavior, so they keep doing it. Have you ever lived in fear of what they might do next, if you will be able to handle them or have to put them in an institution by the time they are a young teen. No one wants to see that, be around that, live with that. Have you ever listened to the screams of a child, whose disorder leads to such behavior being used as a way to get what they want or change what others are doing because it works and no other behavior they are able to use gets such an immediate result. No one wants to listen to that, be around that, live with that. Be ISOLATED. It is much quicker and easier for school staff to ISOLATE these students than to teach them to stop using these behaviors. We live in a society that expects fast food, instant messaging, instant results and gratification all for minimum effort. Heaven forbid it for it to take time and hard work to get results. We, who are the parents of such children are ISOLATED as well. We don't dare take our children to restaurants, sporting events, grocery stores, even large family gatherings because of these behaviors. No one understands our children or us. They

would rather not be around us. We receive stares and or well meaning advice. Mostly we just don't subject ourselves to situations our kids and we can not handle. I know that this is true to some extent for all families with kids with autism and other developmental disorders, but for families dealing with severe behaviors it is a darker reality. Real or imagined I have felt the uneasiness of others even in the autism community towards my son and myself. Real or imagined I have felt like an outsider in the company of others that could most easily understand. So in part, that is why I felt that the policies regarding Seclusion & Restraint needed to be provided to our support group. Everyone, whether they will ever have to deal with this issue or not needs to know that these kinds of things exist and that some of our brothers and sisters in the developmental disorder community have to navigate these dangerous waters. So we need to get this problem out in the open to gain understanding and knowledge, to gain solidarity amongst ourselves. No one should have to deal with autism and other developmental disorders by themselves. No one should have to deal with severe behaviors by themselves. No one should have to deal with Seclusion & Restraint by themselves. We need to stand together. Also no one really knows until it happens if they will be dealing with severe behaviors. With kids with communication deficits it is always a possibility. We need to be informed and proactive. Break through the isolation we feel, real or imagined. Help each other's children by becoming educated about these issues and making sure other parents know that they do not have to consent to these procedures being included in their child's IEP or Behavior Plan. These procedures can already be used without their consent if the situation is that dangerous. Help each other by making sure other parents are educated about other types of behavior management strategies that are more humane and much

more effective for stopping these behaviors. Help each other by educating other parents about ways to negotiate with IEP teams and effectively advocate for their children to keep these procedures from being used. Becoming educated and eliminating the isolation will go a long way towards stopping or minimizing these procedures from becoming the “go to” behavior interventions to being almost never used.

Educated parents will go a long way towards getting schools to bring in trained staff or educate their staff about these procedures that can actually escalate and reinforce the behaviors that they are trying to stop and damage the emotional well being of our kids that is already so fragile. Schools need trained staff that is able to do Functional Behavioral Analysis to determine why these kids do what they do and find replacement behaviors so that they do not have to use these behaviors to get what they need. Trained staff who can determine problem areas in the environment, needs for staff training, and perform task analysis of the skills that students are learning to determine the education methodologies that would enable the student to learn better, faster, reduce the frustration which in turn will help to reduce the behaviors. Trained staff is needed to make sure that these kids, who have such difficulties in communication, learn a functional, spontaneous, independent form of communication that will help reduce their need to use their severe behaviors as nonverbal modes of communication that too often are the only things that get a response. Trained staff is needed to determine PBIS that address all these areas of concern and need. Trained staff is needed to determine PBIS for students with the potential for severe behaviors to prevent rather than to stop these behaviors. Being proactive will give the best possible outcomes for these students, save money and time

for the school district, save parents from heart aches, schools and parents from head aches and prevent further isolation. One problem for parents is, should you ask a school district about PBIS, of course they are going to say they have trained staff and they are providing appropriate PBIS. Unfortunately the "trained staff" are not always adequately trained and not all "PBIS" are appropriate because they are determined by inadequately "trained staff". It is difficult for schools and parents to get it right on behalf of the students and children. If parents push too much they are considered overzealous, high maintenance or difficult parents. Where the balance should be is difficult to determine. When problem behaviors escalate and parents begin to question what is going on, school districts have the tendency to go on the defensive, limit the information and data that parents are given as well as parent's access to their child in the school setting and to the staff working with the child. School Districts also have the tendency to try to shift the blame away from staff and teaching methodologies. Instead of performing a Functional Behavior Analysis to determine why a child is exhibiting the behaviors, blame is placed on the parents, or the disorder itself. School districts do have the obligation to prevent regression in behavior on their watch. If there is regression in behavior with their "trained staff" and their version of "PBIS" then they have an obligation to seek consultation from experts outside the district to determine the appropriate services needed to reverse the regression and prevent it's reappearance. Parents have the obligation to try to seek help if they are seeing regression in behavior at home. To help parents seek intervention and work with the school district we must put a stop to the isolation.

There **must** be consistency between school and home and so schools AND parents need to be willing work together to determine how to practically implement PBIS in the home environment. This may take home visits by school staff to see how and why behaviors are happening in the home and if the child's response is different in the home environment. School staff needs to train parents so they can effectively implement the behavior plan in the home environment. This takes collaboration, communication and trust between home and school. This is another reason we must stop the isolation - to stop the distrust, the blame game, and misunderstandings that isolation breeds.

PBIS takes trained and experienced staff to determine what should be done and how to implement the procedures and trouble shoot the inevitable unforeseen problems. This is much more time intensive, is ongoing, and takes more expertise than the training on the use of restraint and seclusion procedures. There in lies the problem. I will concede that working with students with developmental disorders and severe behavior problems is VERY challenging and what works for one student doesn't necessarily work for another. One staff member's experience with many students with developmental disorders will not necessarily prepare them for **all** students. Schools are in a hard spot. Funding is being cut over and over. Trained staff costs money. While administrators work to convince parents that S & R 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, all which work to keep this an issue of ISOLATION. If we want change, we need to bring this out in the open, educate our



schools and our parents. We need to do this for the good of our own children, our families, our schools and our communities. We need to stop the isolation, NOW!

Please make these nonbinding guidelines into laws to protect our kids.

Thank you,

Gayla Ward

Gardner, KS