Approved: February 22, 2011
Date

MINUTES OF THE HOUSE CHILDREN AND FAMILIES COMMITTEE

FEBRUARY 10, 2011

The meeting was called to order by Chairman Kiegerl at 9:05 a.m. on February 10, 2011, in Room 142S of the Capitol.

All members were present.

Committee Staff Present:

Jay Hall, Intern, Kansas Legislative Research Department
Renae Jefferies, Office of the Revisor of Statutes
June Christensen, Committee Assistant

Others Attending: See attached list.

Conferees appearing before the committee:

Jane Rhys, Executive Director, Council on Developmental Disabilities
Rocky Nichols, Executive Director, Disability Rights Center of Kansas
Linda Aldridge, ED.D, Legislative Officer, Kansas Association of Special Education Administrators (KASEA)
Terry Collins, Director, Doniphan County Education Cooperative No. 616
Kris A. Ehling, Parent of Child with Disabilities

Written Testimony:

Lee Stickle, Kansas State Department of Education (Attachment 6).
Kathy Kersenbrock-Ostmeyer, Director, Special Education, Parent of Child with Disability (Attachment 7.
Mike Bilderback, Director of Special Education, Wamego School District Attachment 8).
Lesli Girard, Director, Families Together (includes testimony from Aimee Keohane, Jeremy and Rachel Banning, Anonymous Grandparent, Leann Sumpter, Jessica B. Greene, and, Linda Weinmaster) (Attachment 9).
Anonymous Parent (Attachment 10)
Janette Keil, Keys for Networking, Inc. (Attachment 11).
Tom Laing, Executive Director, InterHab (Attachment 12).

Approval of January 25, January 27, February 3, and February 7, 2011, Minutes.

Motion by Representative Bill Wolf, seconded by Representative Meigs, to approve the January 25, January 27, February 3, and February 7, 2011, minutes as presented. The motion carried unanimously.

Jane Rhys, Executive Director, Council on Developmental Disabilities, appeared before the Committee supporting legislation that would make seclusion and restraint of autistic children the same in all Kansas school districts (Attachment 1). She defined autism and noted that the present seclusion and restraint methods often don't work, because the children do not like to be touched. She said a nurturing environment rather than restraint or seclusion is often more effective.

Rocky Nichols, Executive Director of the Disability Rights Center of Kansas, presented testimony in favor of the proposed legislation. He gave a brief history of the seclusion/restraint issue in Kansas that included the *Guidelines* passed by the Kansas State Board of Education (Attachment 2). While it was of help, it does not have any enforceable protections. He cited statistics of deaths and injuries that have happened nationwide as a result of restraint use. He presented two legislative options the Committee might consider and possibly refer to an exempt committee if it could not be advanced by this committee.

Linda Aldridge, Ed.D, Legislative Officer for the Kansas Association of Special Education Administrators (KASEA), spoke in favor of the present system of using the guidelines that were based on federal regulation and what is required by the *Individuals with Disabilities Education Act (IDEA)* (Attachment 3). She reported that no contacts, due process, or dispute resolution claims regarding seclusion/restraint had been received and that the federal guidelines stress that states should strive to minimize special education rules and regulations.

Terry Collins, Director of the Doniphan County Education Cooperative No. 616, also spoke in favor of maintaining the current federal regulations and IDEA requirements (Attachment 4). He quoted statistics showing a minimal number of reports regarding restraint and seclusion issues and that KSDE had not received contacts from the Disabilities Rights Council or Kansas Families Together regarding restraint/seclusion issues.

Kris A. Ehling, parent of a child with disabilities, spoke in favor of stronger mandates for the treatment of children with autism and more consistent use of restraint/seclusion for them (Attachment 5). He said he was a parent of a child with autism and reported the issues encountered with use of restraint/seclusion. He urged the committee to pass legislation mandating consistent policies for using seclusion/restraint into law.

Chairperson Kiegerl said the committee will carefully consider the issues discussed today. He announced that next week's meetings would be hearings on proposed bills.

The meeting was adjourned at 10:30 a.m.

CHILDREN AND FAMILIES COMMITTEE
GUEST LIST

DATE: February 10, 2011

NAME (Please Print)	REPRESENTING
Kris Ehling	Parents
Terry Collins	DCEC #614
Linda Aldred	KASEA
TERRY FORSYTH	KNEA
Judy Martin	USD #231
Tom Krahl	KASB
Steve Solomon	TFI Family Services
Catherine Johnson	DRC
Christy Monsson	DRC/Parent
Carolyn Weinhold	DRC
Kari Presley	Kearney & Associates Inc.
Sue Storm	KS BOE

Kansas Council on Developmental Disabilities

SAM BROWNBACK, Governor
KRISTIN FAIRBANK, Chairperson
JANE RHYS, Ph. D., Executive Director
jrhys@kcdd.org

Docking State Off. Bldg., Rm 141,
915 SW Harrison Topeka, KS 66612
785/296-2608, FAX 785/296-2861
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"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

House Committee on Children and Families

February 10, 2011

Mr. Chairman, members of the Committee, thank you all for the opportunity of presenting some information regarding Autism and the use of seclusion and restraint with children who have Autism. I used to be the Program Specialist at the Department of Education for Autism and Emotional Disturbance. As such I presented at many workshops across Kansas to teachers and principals on the use of seclusion and restraint.

First, as a reminder, the most common feature of Autism is impaired social interaction. To quote the *Autism Fact Sheet* from the National Institute of Neurological Disorders and Stroke (attached):

> Children with ASD may fail to respond to their names and often avoid eye contact with other people. They have difficulty interpreting what others are thinking or feeling because they can't understand social cues, such as tone of voice or facial expressions, and don't watch other people's faces for clues about appropriate behavior. They lack empathy.

In addition, children with Autism typically do not like to be touched. They do not respond normally to parental hugs and are very self-involved. The Kansas Department of Education *Guidelines for the Use of Seclusion Rooms and Restraint on Children with Disabilities* defines restraint as:

> (d) "Mechanical restraint" means any device or object used to limit a person's movement, except that a protective or stabilizing device either

HOUSE CHILDREN AND
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ATTACHMENT NO. 1

> appropriately licensed to issue the order for the device or required by law shall not be considered to be a mechanical restraint.
>
> (e) "Physical restraint" means bodily force used to substantially limit a person's movement, except that consensual, solicited, or unintentional contact and contact to provide comfort, assistance, or instruction shall not be deemed to be physical restraint.

Given that the child with Autism does <u>not</u> like to be touched, the use of physical restraint is inherently a very punishing act and thus should not be used unless the child is in imminent danger. An example might be running into the path of an oncoming car.

When I did workshops I always counseled education staff to be extremely cautious in the use of restraint. Another problem is that, even if trained in the use of restraint, and I know there are various systems of restraint in which a person can be trained. One always must have the physical ability to do restraint. If you are a 5 foot 1 inch teacher who weighs 100 pounds you will probably have difficulty restraining a child of your own size or larger.

I have also been told that there is a person who is trained on one of the restraint procedures (Mandt) who is working on modifying the procedure specifically for use with children who have Autism. This indicates that the systems used for all children may not be appropriate for use with children with Autism.

Seclusion is defined by the previously mentioned guideline as:

> (g) "Seclusion room" means a room or other confined area in which a child with a disability is placed in isolation from other persons for a limited time as a behavior intervention strategy and from which the student is prevented from having egress.

A more commonly used term is "time-out". This room or place is used for the child as a behavior intervention strategy. Its use, as well as the use of restraint, seems contraindicated given their difficulty interpreting what others are thinking or feeling. They do not relate cause and effect so do not understand that placement in the time out or seclusion place is a result of their behavior. Thus the use of such place as a behavior intervention strategy, designed to teach the child to discontinue bad behavior may not be teaching the child with Autism anything.

Finally, a recent paper *What blame can tell us about Autism,* studies theory-of-mind ability in people with Autism (attached). This theory involves a person's ability to infer the thoughts of other people. In this MIT study, researchers found that persons who have Autism have a inability to evaluate other people's mental states and determine what they know, what they want, why they are happy, sad, angry, or scared. Again, people who have Autism, by the nature of their disability, are unable to understand why they have been restrained or put in a seclusion environment. They cannot relate cause and effect so this method of behavior intervention probably will not produce the desired effect.

Children who have Autism need a nurturing environment designed to meet their unique needs resulting from their disability, not a punishing environment that does not improve their ability to interact appropriately with others. When one considers the possibility of causing harm to the child and even to staff trying to restrain the child, one questions its use except in extreme situations. The use of a seclusion place is also questionable unless one has documented its effectiveness in reducing the child's inappropriate behavior.

We do appreciate appearing before you today and look forward to working with you in meeting the needs of persons who have a developmental disability. Please feel free to contact me with any questions you may have or if you need any information.

Jane Rhys, Ph.D., Executive Director
Kansas Council on Developmental Disabilities
Docking State Office Building, Room 141
915 SW Harrison
Topeka, KS 66612-1570
785 296-2608
jrhys@kcdd.org

ational Institute of
eurological Disorders and Stroke
National Institutes of Health
Reducing the burden of neurological disease...

Autism Fact Sheet

See a list of all NINDS Disorders

Get Web page suited for printing
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Autismo

Table of Contents (click to jump to sections)

What is autism?

Autism spectrum disorder (ASD) is a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. Autistic disorder, sometimes called autism or classical ASD, is the most severe form of ASD, while other conditions along the spectrum include a milder form known as Asperger syndrome, the rare condition called Rett syndrome, and childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS). Although ASD varies significantly in character and severity, it occurs in all ethnic and socioeconomic groups and affects every age group. Experts estimate that three to six children out of every 1,000 will have ASD. Males are four times more likely to have ASD than females.

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What are some common signs of autism?

The hallmark feature of ASD is impaired social interaction. A child's primary caregivers are usually the first to notice signs of ASD. As early as infancy, a baby with ASD may be unresponsive to people or focus intently on one item to the exclusion of others for long periods of time. A child with ASD may appear to develop normally and then withdraw and become indifferent to social engagement.

Children with ASD may fail to respond to their names and often avoid eye contact with other people. They have difficulty interpreting what others are thinking or feeling because they can't understand social cues, such as tone of voice or facial expressions, and don't watch other people's faces for clues about appropriate behavior. They lack empathy.

Many children with ASD engage in repetitive movements such as rocking and twirling, or in self-abusive behavior such as biting or head-banging. They also tend to start speaking later than other children and may refer to themselves by name instead of "I" or "me." Children with ASD don't know how to play interactively with other children. Some speak in a sing-song voice about a narrow range of favorite topics, with little regard for the interests of the person to whom they are speaking.

Children with ASD appear to have a higher than normal risk for certain co-occurring conditions, including Fragile X syndrome (which causes mental retardation), tuberous sclerosis (in which tumors grow on the brain), epileptic seizures, Tourette syndrome, learning disabilities, and attention deficit disorder. About 20 to 30 percent of children with ASD develop epilepsy by the time they reach adulthood. While people with schizophrenia may show some autistic-like behavior, their symptoms usually do not appear until the late teens or early adulthood. Most people with schizophrenia also have hallucinations and delusions, which are not found in autism.

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How is autism diagnosed?

ASD varies widely in severity and symptoms and may go unrecognized, especially in mildly affected children or when it is masked by more debilitating handicaps. Very early indicators that require evaluation by an expert include:

- [illegible] babbling or pointing by age 1
- no single words by 16 months or two-word phrases by age 2
- no response to name
- loss of language or social skills
- poor eye contact
- excessive lining up of toys or objects
- no smiling or social responsiveness.

Later indicators include:

- impaired ability to make friends with peers
- impaired ability to initiate or sustain a conversation with others
- absence or impairment of imaginative and social play
- stereotyped, repetitive, or unusual use of language
- restricted patterns of interest that are abnormal in intensity or focus
- preoccupation with certain objects or subjects
- inflexible adherence to specific routines or rituals.

Health care providers will often use a questionnaire or other screening instrument to gather information about a child's development and behavior. Some screening instruments rely solely on parent observations, while others rely on a combination of parent and doctor observations. If screening instruments indicate the possibility of ASD, a more comprehensive evaluation is usually indicated.

A comprehensive evaluation requires a multidisciplinary team, including a psychologist, neurologist, psychiatrist, speech therapist, and other professionals who diagnose children with ASD. The team members will conduct a thorough neurological assessment and in-depth cognitive and language testing. Because hearing problems can cause behaviors that could be mistaken for ASD, children with delayed speech development should also have their hearing tested.

Children with some symptoms of ASD but not enough to be diagnosed with classical autism are often diagnosed with PDD-NOS. Children with autistic behaviors but well-developed language skills are often diagnosed with Asperger syndrome. Much rarer are children who may be diagnosed with childhood disintegrative disorder, in which they develop normally and then suddenly deteriorate between the ages of 3 to 10 years and show marked autistic behaviors. Girls with autistic symptoms may have Rett syndrome, a sex-linked genetic disorder characterized by social withdrawal, regressed language skills, and hand wringing.

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What causes autism?

Scientists aren't certain about what causes ASD, but it's likely that both genetics and environment play a role. Researchers have identified a number of genes associated with the disorder. Studies of people with ASD have found irregularities in several regions of the brain. Other studies suggest that people with ASD have abnormal levels of serotonin or other neurotransmitters in the brain. These abnormalities suggest that ASD could result from the disruption of normal brain development early in fetal development caused by defects in genes that control brain growth and that regulate how brain cells communicate with each other, possibly due to the influence of environmental factors on gene function. While these findings are intriguing, they are preliminary and require further study. The theory that parental practices are responsible for ASD has long been disproved.

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What role does inheritance play?

Twin and family studies strongly suggest that some people have a genetic predisposition to autism. Identical twin studies show that if one twin is affected, there is a 90 percent chance the other twin will be affected. There are a number of studies in progress to determine the specific genetic factors associated with the development of ASD. In families with one child with ASD, the risk of having a second child with the disorder is approximately 5 percent, or one in 20. This is greater than the risk for the general population. Researchers are looking for clues about which genes contribute to this increased susceptibility. In some cases, parents and other relatives of a child with ASD show mild impairments in social and communicative skills or engage in repetitive behaviors. Evidence also suggests that some emotional disorders, such as manic depression, occur more frequently than average in the families of people with ASD.

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Do symptoms of autism change over time?

For many children, symptoms improve with treatment and with age. Children whose language skills regress early in life—before the age of 3—appear to have a higher than normal risk of developing epilepsy or seizure-like brain activity. During adolescence, some children with ASD may become depressed or experience behavioral problems, and their treatment may need some modification as they transition to adulthood. People with ASD usually continue to need services and supports as they get older, but many are able to work successfully and live independently or within a supportive environment.

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How is autism treated?

There is no cure for ASD. Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement. The ideal treatment plan coordinates therapies and interventions that meet the specific needs of individual children. Most health care professionals agree that the earlier the intervention, the better.

> **Educational/behavioral interventions**: Therapists use highly structured and intensive skill-oriented training sessions to help children develop social and language skills, such as Applied Behavioral Analysis. Family counseling for the parents and siblings of children with ASD often helps families cope with the particular challenges of living with a child with ASD.
>
> **Medications**: Doctors may prescribe medications for treatment of specific ASD-related symptoms, such as anxiety, depression, or obsessive-compulsive disorder. Antipsychotic medications are used to treat severe behavioral problems. Seizures can be treated with one or more anticonvulsant drugs. Medication used to treat people with attention deficit disorder can be used effectively to help decrease impulsivity and hyperactivity.
>
> **Other therapies**: There are a number of controversial therapies or interventions available for people with ASD, but few, if any, are supported by scientific studies. Parents should use caution before adopting any unproven treatments. Although dietary interventions have been helpful in some children, parents should be careful that their child's nutritional status is carefully followed.

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What research is being done?

In 1997, at the request of Congress, the National Institutes of Health (NIH) formed its Autism Coordinating Committee (NIH/ACC) to enhance the quality, pace and coordination of efforts at the NIH to find a cure for autism (http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-pervasive-developmental-disorders/nih-initiatives/nih-autism-coordinating-committee.shtml). The NIH/ACC involves the participation of seven NIH Institutes and Centers: the National Institute of Neurological Disorders and Stroke (NINDS), the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, the National Institute of Mental Health, the National Institute on Deafness and Other Communication Disorders, the National Institute of Environmental Health Sciences, the National Institute of Nursing Research, and the National Center on Complementary and Alternative Medicine. The NIH/ACC has been instrumental in the understanding of and advances in ASD research. The NIH/ACC also participates in the broader Federal Interagency Autism Coordinating Committee (IACC) that is composed of representatives from various component agencies of the U.S. Department of Health and Human Services, as well as the U.S. Department of Education and other government organizations.

In fiscal years 2007 and 2008, NIH began funding the 11 Autism Centers of Excellence (ACE), coordinated by the NIH/ACC. The ACEs are investigating early brain development and functioning, social interactions in infants, rare genetic variants and mutations, associations between autism-related genes and physical traits, possible environmental risk factors and biomarkers, and a potential new medication treatment.

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Where can I get more information?

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

BRAIN
P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
http://www.ninds.nih.gov

Information also is available from the following organizations:

Association for Science in Autism Treatment
P.O. Box 188

Autism National Committee (AUTCOM)
P.O. Box 429

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Crosswicks, NJ 08515-0188
info[illegible]nline.org
http[illegible]satonline.org

Forest Knolls, CA 94933
http://www.autcom.org

Autism Network International (ANI)
P.O. Box 35448
Syracuse, NY 13235-5448
jisincla@syr.edu
http://www.ani.ac

Autism Research Institute (ARI)
4182 Adams Avenue
San Diego, CA 92116
director@autism.com
http://www.autismresearchinstitute.com
Tel: 866-366-3361
Fax: 619-563-6840

Autism Society of America
7910 Woodmont Ave.
Suite 300
Bethesda, MD 20814-3067
http://www.autism-society.org
Tel: 301-657-0881 800-3AUTISM (328-8476)
Fax: 301-657-0869

Autism Speaks, Inc.
2 Park Avenue
11th Floor
New York, NY 10016
contactus@autismspeaks.org
http://www.autismspeaks.org
Tel: 212-252-8584 California: 310-230-3568
Fax: 212-252-8676

Birth Defect Research for Children, Inc.
800 Celebration Avenue
Suite 225
Celebration, FL 34747
betty@birthdefects.org
http://www.birthdefects.org
Tel: 407-566-8304
Fax: 407-566-8341

MAAP Services for Autism, Asperger Syndrome, and PDD
P.O. Box 524
Crown Point, IN 46308
info@aspergersyndrome.org
http://www.aspergersyndrome.org/
Tel: 219-662-1311
Fax: 219-662-1315

National Dissemination Center for Children with Disabilities
U.S. Dept. of Education, Office of Special Education Programs
1825 Connecticut Avenue NW, Suite 700
Washington, DC 20009
nichcy@aed.org
http://www.nichcy.org
Tel: 800-695-0285 202-884-8200
Fax: 202-884-8441

National Institute of Child Health and Human Development (NICHD)
National Institutes of Health, DHHS
31 Center Drive, Rm. 2A32 MSC 2425
Bethesda, MD 20892-2425
http://www.nichd.nih.gov
Tel: 301-496-5133
Fax: 301-496-7101

National Institute on Deafness and Other Communication Disorders Information Clearinghouse
1 Communication Avenue
Bethesda, MD 20892-3456
nidcdinfo@nidcd.nih.gov
http://www.nidcd.nih.gov
Tel: 800-241-1044 800-241-1055 (TTD/TTY)

National Institute of Environmental Health Sciences (NIEHS)
National Institutes of Health, DHHS
111 T.W. Alexander Drive
Research Triangle Park, NC 27709
webcenter@niehs.nih.gov
http://www.niehs.nih.gov
Tel: 919-541-3345

National Institute of Mental Health (NIMH)
National Institutes of Health, DHHS
6001 Executive Blvd. Rm. 8184, MSC 9663
Bethesda, MD 20892-9663
nimhinfo@nih.gov
http://www.nimh.nih.gov
Tel: 301-443-4513/866-415-8051 301-443-8431 (TTY)
Fax: 301-443-4279

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"Autism Fact Sheet," NINDS. Publication date September 2009.

NIH Publication No. 09-1877

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See a list of all NINDS Disorders

Publicaciones en Español

- Autismo

Prepared by:
Office of Communications and Public Liaison
National Institute of Neurological Disorders and Stroke

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Be MD 20892

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Last updated December 20, 2010

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What blame can tell us about autism

Neuroscientists find evidence that autistic patients have trouble understanding other people's intentions.

Anne Trafton, MIT News Office
February 1, 2011

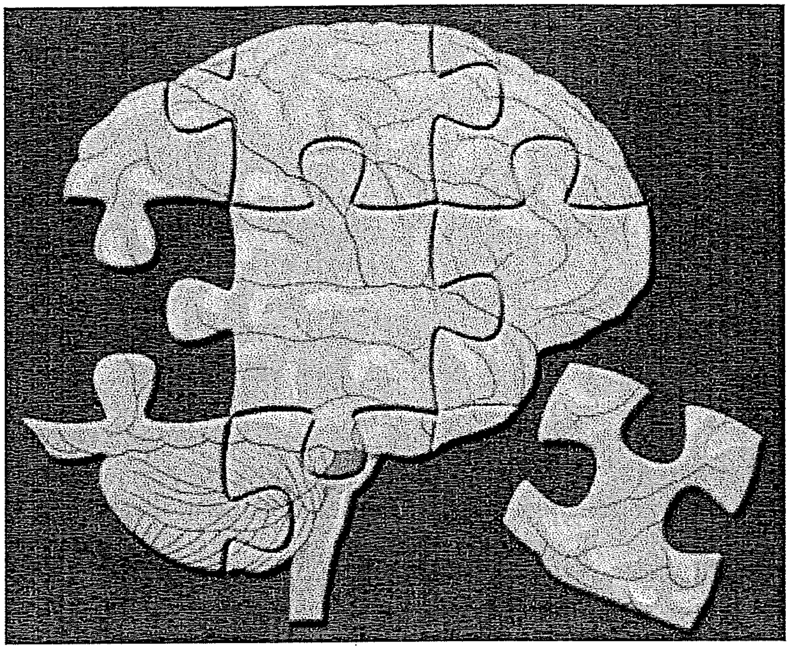

Photo - Graphic: Christine Daniloff

In the mid-1980s, a team of autism researchers theorized that one of the major features of autism is an inability to infer the thoughts of other people. This skill, known as theory of mind, comes naturally to most people — we are constantly evaluating other people's mental states and trying to determine what they know, what they want and why they are happy or sad, angry or scared.

Though there is much anecdotal evidence that this skill is impaired in autistic people, it has been difficult to show it experimentally in adults. Now, a study from MIT neuroscientists reveals that high-functioning autistic adults appear to have trouble using theory of mind to make moral judgments in certain situations.

Specifically, the researchers found that autistic adults were more likely than non-autistic subjects to blame someone for accidentally causing harm to another person. This shows that their judgments rely more on the outcome of the incident than on an understanding of the person's intentions, says Liane Young, an MIT postdoctoral associate and one of the lead authors of the study, which appears in the Jan. 31 online edition of the *Proceedings of the National Academy of Sciences*.

For example, in one scenario, "Janet" and a friend are kayaking in a part of the ocean with many jellyfish. The friend asks Janet if she should go for a swim. Janet has just read that the jellyfish in the area are harmless, and tells her friend to go for a swim. The friend is stung by a jellyfish and dies.

In this scenario, the researchers found that people with autism are more likely than non-autistic people to blame Janet for her friend's death, even though she believed the jellyfish were harmless.

Young notes that such scenarios tend to elicit a broad range of responses even among non-autistic people. "There's no normative truth as to whether accidents should be forgiven. The pattern with autistic patients is that they are at one end of the spectrum," she says. Young's co-lead author on the paper is former MIT postdoctoral associate Joseph Moran, now at Harvard.

Understanding others

Most children develop theory-of-mind ability around age 4 or 5, which can be demonstrated experimentally with "false-belief" tests. In the classic example, a child is shown two dolls, "Sally" and "Anne." The experimenter puts on a skit in which Sally puts a marble in a basket and then leaves the scene. While Sally is away, Anne moves the marble from the basket to a box. The experimenter asks the child where Sally will look for the marble when she returns. Giving the correct answer — that Sally will look in the basket — requires an understanding that others have beliefs that may differ from our own knowledge of the world, and from reality.

Previous studies have shown that autistic children develop this ability later than non-autistic children, if ever,

de ing on the severity of the autism, says the study's senior author, John Gabrieli, the Grover Herm
P or of Health Sciences and Technology.

"High-functioning" autistic people — for example, those with a milder form of autism such as Asperger's syndrome — often develop compensatory mechanisms to deal with their difficulties in understanding other people's thoughts. The details of these mechanisms are unknown, says Young, but they allow autistic people to function in society and to pass simple experimental tests such as determining whether someone has committed a societal "faux pas."

However, the scenarios used in the new MIT study were constructed so that there is no easy way to compensate for impaired theory of mind. The researchers tested 13 autistic adults and 13 non-autistic adults on about 50 scenarios similar to the jellyfish example.

Uta Frith, professor of psychology at the University College London's Institute of Cognitive Neuroscience, was part of the team of scientists who published research in 1985 suggesting that children with autism have impairments of theory of mind. Frith says the new study offers strong support for that hypothesis.

"The study uses a novel test, the judgment of intentions in moral vignettes, to probe the theory. It is an excellent test because it detects poor mentalizing even in individuals with mild autism spectrum disorder who have learned to compensate for their difficulties in understanding mental states," she says.

Building morality

In a 2010 study, Young used the same hypothetical scenarios to test the moral judgments of a group of patients with damage to the ventromedial prefrontal cortex (VMPC), a part of the prefrontal cortex (where planning, decision-making and other complex cognitive tasks occur).

Those patients understand other people's intentions, but they lack the emotional outrage that usually occurs in cases where someone tries (but fails) to harm someone else. For example, they would more easily forgive someone who offers mushrooms he believes to be poisonous to an acquaintance, if the mushrooms turn out to be harmless.

"While autistic individuals are unable to process mental state information and understand that individuals can have innocent intentions, the issue with VMPC patients is that they could understand information but did not respond emotionally to that information," says Young.

Putting these two pieces together could help neuroscientists come up with a more thorough picture of how the brain constructs morality. Previous studies by MIT assistant professor Rebecca Saxe (also an author of the new *PNAS* paper) have shown that theory of mind appears to be seated in a brain region called the right temporoparietal junction (TPJ). In ongoing studies, the researchers are studying whether autistic patients have irregular activity in the right TPJ while performing the moral judgment tasks used in the *PNAS* study.

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Freedom from Unsafe Seclusion & Restraint in Schools

DRC DISABILITY RIGHTS CENTER*of*KANSAS

EQUALITY ♦ LAW ♦ JUSTICE

Rocky Nichols
Executive Director
Voice - 1-877-776-1541; TDD – 1-877-335-3725
www.drckansas.org; rocky@drckansas.org

House Children & Families Committee, February 10, 2011

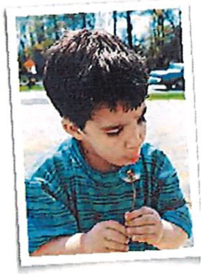
A brief history of the Seclusion/Restraint Issue in Kansas

- 2005 – Kansas Senate considers bill to regulate seclusion and restraint in schools (SB 241).
  - Senate Comm. recommends SBOE (State Board of Education) develop "policies and regulations"
- 2007 – "Guidelines" (or "suggestions") passed by SBOE on the use of Seclusion and Restraint (S/R) in schools.
  - SBOE comes within 1 vote of passing enforceable regulations.
- Since 2007 – KSDE have tracked some data on Seclusion, but not Restraint (which is more damaging)
- Parents & Students still have no enforceable protections against these dangerous tactics – this must change. We have tried to work within the suggestions/guidelines; its not working.

HOUSE CHILDREN AND
FAMILIES
DATE: FEBRUARY 10, 2011
ATTACHMENT NO. 2

What are we asking the Committee to do?

- Asking this Committee to engage on this issue to ensure freedom from unnecessary or unsafe seclusion/restraint in Kansas public schools (given you 2 bill draft options)
  - Create enforceable standards based on the growing national consensus
  - Protect students and teachers for these dangerous tactics
  - Require parental notification of when S/R used on their child
  - Ensure tracking and public reporting of aggregate data
    - Kansas only tracks some data on the use of seclusion
    - Restraint is not tracked, though KSDE staff are considering
    - Limited data shows that participating districts have reported increase in use of seclusion over 2008-2009 school year



"They killed his spirit long before his body."
JANET ROACH
mother of Matthew Goodman, shown at about age 4

- "Matthew Goodman, a teen with autism, spent the last 16 months of his life heavily sedated, in arm splints and a helmet, in New Jersey. The restraints were supposed to keep him from picking at an injury, but his mother believes they contributed to his death at age 14." – Columbus Dispatch 4/24/2005
- **130 S/R deaths from 1999 to 2004.**

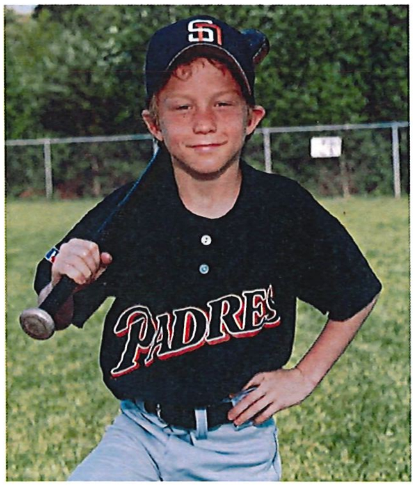
www.pcma.com/crisis_intervention_news/deadly_restraint/faces.stm

Harm of S/R in Schools - Nationally

Cedric Napoleon - Texas death

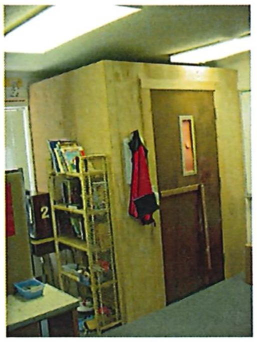
Harm of S/R in Schools – Nationally

Jonathan King – Georgia death



Harm of S/R in Schools

One Example of a Kansas Seclusion Room



Harm of S/R in Schools

A few Kansas Examples – before & after guidelines

- Problem BEFORE guidelines = parents had to move to new school district or hope that the school district would do the right thing on S/R.
- Problem AFTER the guidelines = parents still have to either move or hope schools do the right thing. The only thing that has changed is that they now have some "suggestions" on paper that, *if they know about it*, they can take to their school and present.
- The examples I will be giving are before the guidelines, but the problem is essentially the same.
- Other parents will give testimony about their problems since the guidelines were adopted.

Harm of S/R in Schools

Kansas Examples – before guidelines

- Matthew, a child with cerebral palsy in Scott City, Ks, was secluded in a restroom with a toilet for days, where he was forced to eat and do his work. His mom was forced to change schools to protect her son.
- A Salina parent reported that their child was locked in a dog kennel as a form of seclusion. KSDE refused to investigate, claiming its outside the scope of their regulations and no federal standards exist.
- School personnel strap Ian, a child with Autism in Cheney, in his stiff wooden chair to keep him from fidgeting. He's forced to watch the other kids play. His parents are never told and find out by sheer will.

Harm of S/R in Schools

Kansas Examples – before guidelines

- An Emporia child on the Autism spectrum spends up to 5 hours a day in seclusion, 4 days a week.
- Zach, a child with disabilities in Chanute, Ks, was injured by an untrained aid with an improper hold.
- A Doctor at KU Med writes to a school in Johnson County to stop putting a child with PTSD in a seclusion room because it worsens his emotional disabilities. The school increases its use after receiving the letter. The family is forced to move to a different school district to stop the abuse.

Seclusion & Restraint in Schools – The Final Frontier

- Why are enforceable requirements in schools on Seclusion and Restraint (S/R) so important?
  - Schools are literally the "Final Frontier" of places where seclusion and restraint are not regulated.
- S/R is *closely regulated* in Kansas hospitals, PRTFs, long-term care facilities, intermediate care facilities, day care, etc. Everywhere but schools.
  - Kids spend the most time at school, but receive the least protection for the use of these dangerous tactics (S/R).

The Final Frontier Continued …

- Currently, no state or federal law governing use of Seclusion or Restraint in schools
- Bill has passed US House (introduced in US Senate) … but it is unclear if Congress will pass this law.
- We should not wait for an act of Congress to protect our students and teachers against these dangerous and deadly tactics
- These are dangerous tactics that need to be controlled through enforceable law/rules to protect students, teachers and parents.

Dangerous tactics, regulated everywhere else

- ☐ Many injuries & deaths due to S/R. 130 people in US died during 5 year period from S/R (HHS/CMS).
- ☐ Hartford Courant Paper – exposed problems in S/R

http://www.pcma.com/crisis_intervention_news/deadly_restraint/index.stm
http://www.pcma.com/crisis_intervention_news/deadly_restraint/faces.stm

- ☐ S/R is closely regulated and controlled in almost every other setting that youth with disabilities are served -- state hospitals, PRTFs, long-term care facilities, ICFs/MR, providers of services paid by SRS, etc ... why not schools?
- ☐ Why do we allow the place where children spend the most time (schools) be the place where they get the least protection?
- ☐ 2009 GAO Report found "hundreds of cases" of abuse and death related to S/R. GAO found no data collection, no federal restrictions, and "widely divergent" state protections

Harm of S/R
Staff get hurt, too.

- Assumption – S/R keep staff safe, but the opposite is true
- Data isn't tracked in schools, but for every 100 mental health aides, 26 injuries reported do to the use of S/R (1996 survey)
- MH aide that engages in S/R more dangerous job than lumber, construction & mining
- When S/R use is reduced, injuries to staff and consumers decrease.

Growing National Consensus to Limit S/R

- **This consensus needs to extend to schools. Consensus clearly shows that the requirements must be binding to ensure adequate protections**
- **President Bush's New Freedom Initiative -**

  ". . . Seclusion and restraint are safety interventions of last resort; they are not treatment interventions. In light of the potentially serious consequences, seclusion and restraint should be used only when an imminent risk of danger to the individual or others exists and no other safe, effective intervention is possible."
- **Federal Govt / HHS Official Policy –** S/R must be dramatically reduced & eventually eliminated.

Growing National Consensus on S/R

- **Child Health Act of 2000 –** limits use of seclusion and restraint to "emergency" situations for young people up to age 21 in public facilities and other settings.
- **National State Mental Health Program Directors Position –** "seclusion and restraints, including 'chemical restraints,' are safety interventions of last resort and are not treatment interventions. Seclusion and restraint should never be used for the purposes of discipline, coercion, or staff convenience, or as a replacement for adequate levels of staff or active treatment."
- **Many other states have adopted** similar regulations limiting S/R in schools, regardless of party or ideology (conservative - Texas, moderate – Maine, and liberal states – Massachusetts.

Growing National Consensus on S/R

- American Psychological Assoc. (APA),
- American Medical Assoc. (AMA),
- American Academy of Pediatrics (AAP),
- American Academy of Child and Adolescent Psychology (AACAP)
- International Society of Psychiatric-Mental Health Nurses (ISPN)
  - All these groups have taken positions that restraint should be a tactic of last resort and as emergency interventions to maintain safety (try least restrictive first)
  - All call for staff training, other protections, etc.

Growing National Consensus on S/R

- Autism National Committee – call on Congress and State Legislatures to limit restraint on children w/ disabilities (brief, emergencies only involving serious threat of injury to self or others, etc.). Recommended standardized reporting procedure.
- Child Welfare League of America – call for minimum national standard on training, research on crisis prevention models, etc.

School & Disability Support for US House Bill

- Another indicator of consensus … Over 100 school and disability groups endorsed the US House bill (HR 4247), including:
  - *National School Boards Association,*
  - Autism Society,
  - *National Association of School Psychologists,*
  - United Cerebral Palsy,
  - *National Association of Secondary School Principals,*
  - *AFT (largest teacher's union in US),*
  - Easter Seals
  - National Disability Rights Network & and many more…

Examples of *minimum* elements and components of effective Seclusion/Restraint (S/R) requirements:

- **You don't have to reinvent the wheel – State Board's "guidelines" are good standards – just need to be enforceable & not 'suggestions.' Including:**
- **Use S/R only when student is a imminent risk of harm to self or others**
- **Threshold for S/R use: "immediate and impending threat of causing substantial physical injury to self or others."**
- **Outlaw mechanical and chemical restraint**
- Mechanical restraint – any device or object used to limit a person's movement
- Property damage should only be considered imminent risk of harm if the actions otherwise meet the definition.

Key Minimum elements continued …

- Use of S/R is an intervention of last resort, other interventions must be tried first
- **Establish policy in law to be free from unreasonable, unsafe, & unwarranted use of S/R**
- **Don't use S/R when there's a medical contraindication**
- Restraint is a safety intervention only - not treatment or educational intervention
- If seclusion is used as a behavioral intervention, must have protections in the IEP and standards to ensure it is not abused.

Key Minimum Elements Continued…

- **Require staff training prior to use of S/R (with altercation exception)**
- Require staff to observe and hear the student while in the Seclusion room
- Prohibit locked seclusion rooms
- **Require parental notification of S/R**
- **Require student-level data tracking of both the incidences of S/R (track trends and data to impact future policies)**
- **Issue public reports for accountability**

Key Minimum Elements Continued...

NDRN S/R Committee Guiding Principles:

- School-wide use of positive behavioral supports (PBS) and well trained staff
- S/R = measures of last resort; only for emergency & substantial threat of serious harm to self and others. Not therapeutic interventions, safety interventions.
- Training of staff (PBS, safe use, etc.)
- Constant supervision of S/R during & after use
- Staff must follow specific policies
- Use of S/R is a failure of the schools PBS system
- On-going Goal = reduction of S/R & improve PBS
- Don't use when medical contraindication
- Parents must play an integral role
- Notify parents

Thank you ... what we are asking

- Asking this Committee to have an Exempt Committee (ex: Fed & State) introduce a bill to ensure freedom from unnecessary or unsafe seclusion and restraint, protecting students & teachers. Have this Committee hold hearings on that bill.
  - We have provided you two bill options:
    - Option 1 puts into law the "guideline" language and makes it enforceable, adding appropriate specificity.
    - Option 2 sets the policy and puts the definitions and the most important standards into state law ... has KSDE/ State Board of Ed adopt the rules and regulations to carry out the policy.

Option 1 – Framework for a Bill to Ensure Proper use of Effective Seclusion and Restrain in Public Schools

Note: this option takes the current "guidelines" on seclusion and restraint and makes them enforceable through state law (changes "should" to "shall").

This act may be cited as the freedom from unsafe restraint and seclusion act.

1. Definitions. As used in this statute, the following terms shall have the meanings specified herein:
(a) "Children with disabilities" has the meaning specified in K.S.A. 72-962 and amendments thereto.
(b) "Imminent risk of harm" means an immediate and impending threat of a person causing substantial physical injury to self or others. Violent action that destroys substantial property may fall within this standard only if the property destruction also poses an immediate and impending threat of causing substantial physical injury to self or others.
(c) "Individualized education plan" and "IEP" have the meaning specified in K.S.A. 72-962 and amendments thereto.
(d) "Mechanical restraint" means any device or object used to limit a person's movement, except that a protective or stabilizing device either ordered by a person appropriately licensed to issue the order for the device or required by law shall not be considered to be a mechanical restraint. This term does not include any device used by a law enforcement officer, campus police officer, or school security officer in carrying out law enforcement duties.
(e) "Physical restraint" means bodily force used to substantially limit a person's movement, except that consensual, solicited, or unintentional contact and contact to provide comfort, assistance, or instruction shall not be deemed to be physical restraint.
(f) "School employees" means teachers, paraprofessionals, providers of related services, administrators, and support staff.
(g) "Seclusion room" means a room or other confined area in which a child with a disability is placed in isolation from other persons for a limited time from which the student is prevented from having egress.
(h) "Altercation" means a fight involving a student. Any student possessing a weapon qualifies as an altercation.

2. Seclusion rooms; use and restrictions. (a) No child with a disability shall be subjected to unreasonable, unsafe, or unwarranted use of seclusion rooms. A child shall not be placed in a seclusion room for purposes of discipline or punishment, or for the convenience of staff.
(b) Any child with a disability shall be placed in a seclusion room only if this action is specified in the student's IEP or behavior intervention plan (BIP) or if the behavior of the student presents an imminent risk of harm.
(c) Unless the behavior of a child with a disability presents an imminent risk of harm, the child shall not be placed in a seclusion room unless other less-restrictive, positive behavior intervention strategies specified in the child's IEP or BIP, as appropriate to the

behavior exhibited by the child, have been implemented but were ineffective.

(d)(1) If the IEP team of a child with a disability determines, based upon the results of a functional assessment of behavior and other relevant information, that an appropriate behavior intervention plan for the child should include the use of a seclusion room, the IEP team may include this information in the child's IEP or BIP and shall specify the location of each seclusion room to be used, the maximum length of any period of seclusion, the number of times during a single school day that the child is to be placed in a seclusion room, and any other relevant matter agreed to by the IEP team.

(2) If the use of a seclusion room is an option in the IEP or BIP, the IEP team also shall specify the data to be collected to determine whether placement of the child in a seclusion room is effective with the child, including the number of times that the use of a seclusion room within a fixed period of time could signify the need for an IEP team meeting, and a date by which a review of the effectiveness of this intervention should shall be made and the name of each reviewer. A parent must be given the opportunity to participate in this review. The initial review date should be scheduled for a date not exceeding 45 school days after the IEP team meeting. An IEP team meeting may be requested at any time to review and consider making changes in the use of this behavior intervention strategy.

(e) A child with a disability shall not be placed in a seclusion room if the child is known to have any medical condition that a licensed health care provider has indicated, in a written statement that is provided to the school and that is on file with the school, precludes this action.

(f) A child with a disability shall not be placed in a seclusion room except by a school employee who has had training in the appropriate use of seclusion rooms, including getting a child to a seclusion room, placing a child in a seclusion room, and supervising a child while the child is in the room. The training shall be from training programs approved by the Kansas State Department of Education to ensure that school employees are trained in the proper and safe use of seclusion rooms.

(g) While a child with a disability is in a seclusion room, the school employee who is supervising the student shall be able to see and hear the student at all times.

(h) Not more than one child with a disability shall be placed in the same seclusion room at the same time.

3. Seclusion rooms; size and characteristics. Each seclusion room to be used for any particular child shall be of a size that is appropriate to the child's chronological and developmental age, size, and behavior.

(b) Each seclusion room shall have a ceiling height that is comparable to the ceiling height of the other rooms in the building in which it is located and shall be equipped with heating, cooling, ventilation, and lighting systems that are comparable to the systems that are in use in the other rooms of the building in which it is located.

(c) Each seclusion room shall be free of any object that poses a danger to the child with a disability who is being placed in the room.

(d) Any seclusion room equipped with a locking door shall ensure that the lock automatically disengages when the teacher or attendant viewing the child walks away from the seclusion room.

4. Physical restraint and mechanical restraint; use and restrictions. (a) No child with a disability shall be subjected to unreasonable, unsafe, or unwarranted use of physical restraint. A child with a disability shall not be subjected to any form of mechanical restraint.
(b) Except as provided in paragraph (c), no school employee shall use physical restraint on any child with a disability. Physical restraint shall not be used for discipline, punishment, or the convenience of staff.
(c)(1) A school employee shall use physical restraint on a child with a disability only if the child's behavior presents an imminent risk of harm or the child is involved in an altercation. Except to intercede in an altercation, each school employee applying physical restraint shall use a method of physical restraint in which the employee has received training and should apply the physical restraint in a manner that is proportionate to the circumstances and to the child's size and age and the severity of the child's behavior.
(2) School employees shall be provided training in using an appropriate method of physical restraint and in determining the circumstances in which the use of physical restraint is appropriate. The training shall be from training programs approved by the Kansas State Department of Education to ensure that school employees are trained in the proper use of physical restraint to prevent harm to students or others.

5. Seclusion rooms and physical restraint; reports and notification.
(a)(1) When any child with a disability is placed in a seclusion room or is subjected to physical restraint, the parent of the child shall be notified promptly in a method and manner approved by the Kansas State Department of Education. When there is a question as to whom is authorized to receive such notifications, the school shall notify the same individual or individuals as if it was an Individualized Education Plan matter.
(2) As soon as possible after use of the seclusion room or physical restraint, the school employee who used the seclusion room or physical restraint, or an employee who witnessed its use, shall document the use of the seclusion room or the physical restraint. This documentation shall be completed not later than the school day following the day on which the seclusion room or physical restraint is used, and a copy of the documentation will be provided to the parent of the child when the documentation is completed.
(b)(1) Each school that uses a seclusion room must submit annually to the state director of special education the following information:
(A) The name of the school and the grades offered at the school; and
(B) The length, width and height of each of the seclusion rooms located in the school.
(2) Each school that either restrains a child or uses a seclusion room must submit a quarterly report to the Kansas State Department of Education that includes at least the following information:
(A) The number of students placed in seclusion during the reporting period along with other information on the incidences, including the maximum amount of time any child was in seclusion on a single occasion, and the maximum number of times during a single day that a student was placed in a seclusion room.
(B) The number of students physically restrained during the reporting period along with

other information on the incidences, including the maximum amount of time any child was restrained on a single occasion, and the maximum number of times during a single day that a child was physically restrained.
(C) Other information as decided by the Kansas State Department of Education. In deciding such other information to be collected, the Department shall collect sufficient information and data to ensure that patrons, policymakers and the public can gain a clear picture of the depth and breadth of the use of seclusion and restraint in Kansas schools. The purpose of the information and data collected is to provide detailed information so that policymakers can identify trends and opportunities in order to help reduce the use seclusion and restraint in public schools.
(c) The Kansas State Department of Education will compile the reports from the schools and provide the results to the State Special Education Advisory Council (SEAC), which is to consider the information and make any recommendations it believes appropriate to the State Board of Education. Once provided to the SEAC, these reports will be public information and readily available. In issuing these reports, the Kansas State Department of Education will ensure that as much information and data as possible is provided to the public on the use of seclusion and restraint in order to allow patrons, policymakers and the public to be able to compare the data on the use and incidences between school districts and individual schools. In compiling this aggregate data, individual student confidentiality shall be reasonably protected.

This act shall take effect upon publication in the Kansas Statutes.

Option 2 – Framework for a Bill to Ensure Proper use of Effective Seclusion and Restrain in Public Schools

Note: this option creates definitions and sets the official policy and empowers KSDE OR the State Board of Education to promulgate rules and regulations to carryout the policy.

This act may be cited as the freedom from unsafe restraint and seclusion act.

1. Definitions. As used in this statute, the following terms shall have the meanings specified herein:
(a) "Children with disabilities" has the meaning specified in K.S.A. 72-962 and amendments thereto.
(b) "Imminent risk of harm" means an immediate and impending threat of a person causing substantial physical injury to self or others. Violent action that destroys substantial property may fall within this standard only if the property destruction also poses an immediate and impending threat of causing substantial physical injury to self or others.
(c) "Individualized education plan" and "IEP" have the meaning specified in K.S.A. 72-962 and amendments thereto.
(d) "Mechanical restraint" means any device or object used to limit a person's movement, except that a protective or stabilizing device either ordered by a person appropriately licensed to issue the order for the device or required by law shall not be considered to be a mechanical restraint. This term does not include any device used by a law enforcement officer, campus police officer, or school security officer in carrying out law enforcement duties.
(e) "Physical restraint" means bodily force used to substantially limit a person's movement, except that consensual, solicited, or unintentional contact and contact to provide comfort, assistance, or instruction shall not be deemed to be physical restraint.
(f) "School employees" means teachers, paraprofessionals, providers of related services, administrators, and support staff.
(g) "Seclusion room" means a room or other confined area in which a child with a disability is placed in isolation from other persons for a limited time from which the student is prevented from having egress.
(h) "Altercation" means a fight involving a student. Any student possessing a weapon qualifies as an altercation.

2. Seclusion rooms and physical restraint; use and restrictions. (a) No child with a disability shall be subjected to unreasonable, unsafe, or unwarranted use of physical restraint or seclusion rooms. A child shall never be physically restrained or placed in a seclusion room for purposes of discipline or punishment, or for the convenience of staff. A child with a disability shall not be subjected to any form of mechanical restraint.
(b) Any child with a disability shall be placed in a seclusion room or physically restrained only if the behavior of the student presents an imminent risk of harm. However, if the child is involved in an altercation then physical restraint may still be used even if the imminent risk of harm standard is not met.
(c) A child with a disability shall not be placed in a seclusion room if the child is known to have any medical condition that a licensed health care provider has indicated, in a written statement that is provided to the school and that is on file with the school,

precludes this action.
(d) A child with a disability shall not be physically restrained or placed in a seclusion room except by a school employee who has had training in the appropriate use of these techniques. Such training shall be from training programs approved by the Kansas State Department of Education to ensure that school employees are trained in the proper and safe use of seclusion rooms. This training requirement shall not apply if the child is involved in an altercation.
(e) While a child with a disability is in a seclusion room, the school employee who is supervising the student shall be able to see and hear the student at all times.
(f) Not more than one child with a disability shall be placed in the same seclusion room at the same time.
(g) Any seclusion room equipped with a locking door shall ensure that the lock automatically disengages when the teacher or attendant viewing the child walks away from the seclusion room.
(h) If a school has a seclusion room, it will be a safe place with proportional and similar characteristics as other rooms where students frequent.

3. Reports and parental notification.
(a) When any child with a disability is placed in a seclusion room or is subjected to physical restraint, the school employee who used the seclusion room or physical restraint, or an employee who witnessed its use, shall document the use of the seclusion room or the physical restraint. This documentation shall be completed not later than the school day following the day on which the seclusion room or physical restraint is used, and a copy of the documentation will be provided to the parent of the child when the documentation is completed. When there is a question as to whom is authorized to receive such documentation, the school shall notify the same individual or individuals as if it was an Individualized Education Plan matter.
(b) Each public school will submit information and data on the use of seclusion and restraint as required by the Kansas State Department of Education. At a minimum, the Department shall collect sufficient information and data to ensure that patrons, policymakers and the public can gain a clear picture of the depth and breadth of the use of seclusion and restraint in Kansas schools. The purpose of the information and data collected is to provide detailed information so that policymakers can identify trends and opportunities in order to help reduce the use seclusion and restraint in public schools.
(c) The Kansas State Department of Education will compile the reports from the schools and provide the results to the public. In issuing these reports, the Kansas State Department of Education will ensure that as much information and data as possible is provided to the public on the use of seclusion and restraint in order to allow patrons, policymakers and the public to be able to compare the data on the use and incidences between school districts and individual schools. In compiling this aggregate data, individual student confidentiality shall be reasonably protected.

4. (a) The Kansas State Department of Education ***OR*** State Board of Education shall promulgate rules and regulations to carry out the policies of this act.
[note to Committee: the Revisor will have to decide which entity should be listed with rule making authority].
This act shall take effect upon publication in the Kansas Statutes.

To: Kansas House Children and Families Committee
Kansas Special Education Advisory Council

From: Linda Aldridge, Ed.D.
Legislative Officer
Kansas Association of Special Education Administrators (KASEA)

Date: February 7, 2011

Approximately five years ago, the State Board of Education charged KSDE with the responsibility of bringing together various groups with different perspectives to write guidelines for use of seclusion. KSDE staff, along with representatives of state organizations, was successful in this endeavor.

- During the past four years, (since seclusion guidelines were developed), KSDE has received no contacts from the Disabilities Rights Council or from Kansas Families Together regarding seclusion and/or restraint issues.
- During the past three school years, there were no due process or dispute resolution claims involving seclusion and/or restraint.

It is the position of the Kansas Association of Special Education Administrators (KASEA) that current seclusion guidelines provide appropriate technical support regarding the use of seclusion. In addition, current State Procedural Guidelines for Special Education provide avenues necessary and appropriate to exercise parental rights, to safeguard student safety, and to settle disputes.

Furthermore, it is KASEA's position that Kansas policy and procedures should mirror Federal regulation and not go beyond that which is required by the Individuals with Disabilities Education Act (IDEA). Federal IDEA regulations specifically stress that states must strive to minimize the number of rules and regulations to which special education is subjected.

Thank you for your consideration of KASEA's thoughts regarding seclusion guidelines. If you require further information, I can be reached at:

(785) 295-3089
laldrid@topeka.k12.ks.us

HOUSE CHILDREN AND
FAMILIES
DATE: FEBRUARY 10, 2011
ATTACHMENT NO. 3

DONIPHAN COUNTY EDUCATION COOPERATIVE No. 616
PO Box 399 Troy, KS 66087 785-982-4204
Terry E. Collins, Director

To: House Standing Committee on Children and Families

From: Terry Collins, Ed.S
Director DCEC # 616
Legislative Team
Kansas Association of Special Education Administrators
February 10, 2011

I concur with the position of the Kansas Association of Special Education Administrators (KASEA) regarding guidelines for seclusion and/or restraint. I am a proponent of maintaining the current guidelines and an opponent of developing regulations that do not mirror the federal regulations and which go beyond the requirements of IDEA.

- School districts are required to report quarterly to the State Director of Special Education all incidents of seclusion.
- Less than 20% of the 1380 Public Schools in Kansas reported even having a seclusion room for the 2009-2010 school year
- Less than 1% of the students with disabilities were reported being secluded in each quarter for the 2009-2010 school year.
- Less than 1% of the schools in Kansas secluded more than 5 students per quarter for the entire school year.
- Four was the largest number of students secluded for 60 minutes or more in any quarter for the 2009-2010 school year.
- No (zero) schools reported having secluded a student for 120 minutes or more for the 2009-2010 school year.
- Less than 5% of the schools in Kansas secluded 1-2 students per quarter for the entire 2009-2010 school year.

I stress the point again, since the guidelines were developed, KSDE has received no contacts from either the Disabilities Rights Council or from Kansas Families Together regarding seclusion and/or restraint issues.

The State Department of Education intends to continue professional development through the Technical Assistance Network (TASN) regarding seclusion/restraint. They also plan to provide quarterly seclusion incident data to the directors of special education.

USD 114 Riverside USD 429 Troy USD 111 Doniphan West

HOUSE CHILDREN AND
FAMILIES
DATE: FEBRUARY 10, 2011
ATTACHMENT NO 4

Guidelines for the Use of Seclusion Rooms and Restraint on Children with Disabilities

Guideline 1. Definitions. As used in these guidelines, the following terms shall have the meanings specified herein: (a) "Children with disabilities" has the meaning specified in K.S.A. 72-962 and amendments thereto.

(b) "Imminent risk of harm" means an immediate and impending threat of a person causing substantial physical injury to self or others. Violent action that is destructive of property may involve a substantial risk of injury to a person.

(c) "Individualized education plan" and "IEP" have the meaning specified in K.S.A. 72-962 and amendments thereto.

(d) "Mechanical restraint" means any device or object used to limit a person's movement, except that a protective or stabilizing device either ordered by a person appropriately licensed to issue the order for the device or required by law shall not be considered to be a mechanical restraint. This term does not include any device used by a law enforcement officer, campus police officer, or school security officer in carrying out law enforcement duties.

(e) "Physical restraint" means bodily force used to substantially limit a person's movement, except that consensual, solicited, or unintentional contact and contact to provide comfort, assistance, or instruction shall not be deemed to be physical restraint.

(f) "School employees" means teachers, paraprofessionals, providers of related services, administrators, and support staff.

(g) "Seclusion room" means a room or other confined area in which a child with a disability is placed in isolation from other persons for a limited time as a behavior intervention strategy and from which the student is prevented from having egress.

Guideline 2. Seclusion rooms; use and restrictions. (a) No child with a disability should be subjected to unreasonable, unsafe, or unwarranted use of seclusion rooms. Therefore, a child should be placed in a seclusion room only as a behavior intervention strategy and not for purposes of discipline or punishment, or for the convenience of staff.

(b) Any child with a disability should be placed in a seclusion room only if this action is specified in the student's IEP or behavior intervention plan (BIP) or if the behavior of the student presents an imminent risk of harm.

(c) Unless the behavior of a child with a disability presents an imminent risk of harm, the child should not be placed in a seclusion room unless other less-restrictive, positive behavior intervention strategies specified in the child's IEP or BIP, as appropriate to the behavior exhibited by the child, have been implemented but were ineffective.

(d)(1) If the IEP team of a child with a disability determines, based upon the results of a functional assessment of behavior and other relevant information, that an appropriate behavior intervention plan for the child should include the use of a seclusion room, the IEP team should include this information in the child's IEP or BIP and specify the location of each seclusion room to be used, the maximum length of any period of seclusion, the number of times during a single school day that the child is to be placed in a seclusion room, and any other relevant matter agreed to by the IEP team.

(2) The IEP team also should specify the data to be collected to determine whether placement of the child in a seclusion room is effective with the

child, including the number of times that the use of a seclusion room within a fixed period of time could signify the need for an IEP team meeting, and a date by which a review of the effectiveness of this intervention should shall be made and the name of each reviewer. A parent must be given the opportunity to participate in this review. The initial review date should be scheduled for a date not exceeding 45 school days after the IEP team meeting. Of course, an IEP team meeting may be requested at any time to review and consider making changes in the use of this behavior intervention strategy.

(e) A child with a disability should not be placed in a seclusion room if the child is known to have any medical condition that a licensed health care provider has indicated, in a written statement that is provided to the school and that is on file with the school, precludes this action.

(f) A child with a disability should not be placed in a seclusion room except by a school employee who has had training in the appropriate use of seclusion rooms, including getting a child to a seclusion room, placing a child in a seclusion room, and supervising a child while the child is in the room. The training shall be consistent with nationally-recognized training programs, such as Mandt or Nonviolent Crisis Intervention, to ensure the safe use of this behavior intervention strategy.

(g) While a child with a disability is in a seclusion room, the school employee who is supervising the student should have the ability to see and hear the student at all times.

(h) Not more than one child with a disability should be placed in the same seclusion room at the same time.

Guideline 3. Seclusion rooms; size and characteristics. Each seclusion room to be used for any particular child should be of a size that is appropriate to the child's chronological and developmental age, size, and behavior.

(b) Each seclusion room should have a ceiling height that is comparable to the ceiling height of the other rooms in the building in which it is located and should be equipped with heating, cooling, ventilation, and lighting systems that are comparable to the systems that are in use in the other rooms of the building in which it is located.

(c) Each seclusion room should be free of any object that poses a danger to the child with a disability who is being placed in the room.

(d) Any seclusion room should be equipped with a door that locks only if the lock is equipped with a device that automatically disengages the lock in case of an emergency, such as a fire or tornatic weather.

Guideline 4. Physical restraint and mechanical restraint; use and restrictions. (a) No child with a disability should be subjected to unreasonable, unsafe, or unwarranted use of physical restraint as provided in this guideline. A child with a disability should not be subjected to any form of mechanical restraint.

(b) Except as provided in paragraph (c), no school employee should use physical restraint on any child with a disability. Physical restraint should not be used for discipline, punishment, or the convenience of staff.

(c)(1) A school employee should use physical restraint on a child with a disability only if the child's behavior presents an imminent risk of harm or the child is involved in an altercation. Except to intercede in an altercation, each school employee applying physical restraint should use a method of physical restraint in which the employee has received training and should apply the physical restraint in a manner that is proportionate to the circumstances and to the child's size and age and the severity of the child's behavior.

(2) School employees should be provided training in using an appropriate method of physical restraint and in determining the circumstances in which the use of physical restraint is appropriate. The training should be consistent with nationally-recognized training programs, such as Mandt or Nonviolent Crisis Intervention, to ensure that school employees are trained in the proper use of physical restraint to prevent harm to students or others.

Guideline 5. Seclusion rooms and physical restraint; reports and notification.

(a)(1) When any child with a disability is placed in a seclusion room or is subjected to physical restraint, the procedures specified in this guideline, or others providing for parental notification, should be implemented.

(2) As soon as possible after use of the seclusion room or physical restraint, the school employee who used the seclusion room or physical restraint, or an employee who witnessed its use, should document the use of the seclusion room or the physical restraint. This documentation should be completed not later than the school day following the day on which the seclusion room or physical restraint is used, and a copy of the documentation provided to the parent of the child when the documentation is completed.

(b)(1) Each school that uses a seclusion room as defined in guideline 1 must submit annually to the state director of special education the following information:

(A) The name of the school and the grades offered at the school; and

(B) The length, width and height of each of the seclusion rooms located in the school.

(2) Each school that uses a seclusion room must submit a quarterly report to the state director of special education that includes the following information:

(A) The number of students placed in seclusion during the reporting period;

(B) the maximum amount of time any child was in seclusion on a single occasion; and

(C) the maximum number of times during a single day that a student was placed in a seclusion room.

(c) The state director of special education will compile the reports from the schools and provide the results to the State Special Education Advisory Council, which is to consider the information and make any recommendations it believes appropriate to the State Board of Education.

Written Testimony

of

Kris A. Ehling

before

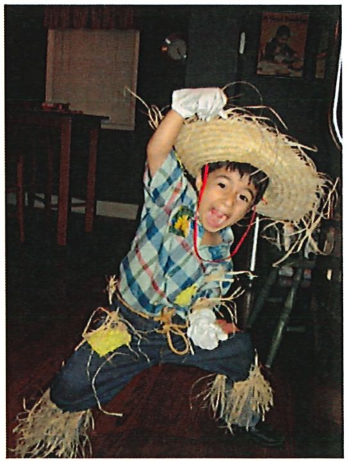
the

House Committee on Children and Families

February 10, 2011

HOUSE CHILDREN AND
FAMILIES
DATE: FEBRUARY 10, 2011
ATTACHMENT NO 5

My name is Kris Ehling. My partner, Bart Flickinger, and I are parents to Ike. We are both educators, live in Wichita, and are proud to call Kansas our home. Our families live nearby in Sterling, Abbyville, and Hutchinson. We came late to the idea of children as I was 40 and Bart 39 when we adopted Ike in July of 2000 when he was just 7 months old. He came with two teeth, a beautiful smile, chubby cheeks, and an indomitable spirit! Like any new parents, we were excited, scared to death, and proud beyond belief.



Over the course of the next 10 and one half years Ike has grown and we have learned of his multiple challenging diagnoses. These challenges were not always understood by us or others. Yet, he continues to excite us, scare us and make us proud

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beyond belief. He loves dressing up in costumes to act out the most recent story or movie. Some of his diagnoses actually have quite positive elements that support all of this creativity. We thought this creativity would be a great advantage to him when he began school.

Beginning school was the start of the tale that brings me before you today. While Ike had a rough Kindergarten year, he had a fantastic 1st grade year in 2007 due to an amazing collaborative relationship between two highly skilled teachers; one regular classroom teacher and the other a special education teacher. In March of 2007, the *Guidelines for the Use of Seclusion Rooms and Restraint on Children with Disabilities* were placed in effect. This is important as the rest of the events of my story occurred *<u>after</u>* the *Guidelines* were placed in effect. Schools were following the *Guidelines* on a voluntary basis. However, it was not our experience that schools actually followed them.

The magic of that 1st grade year would not be repeated. The special education teacher, who had decades of experience, got a new position and was replaced with a Transition to Teaching teacher, who had NO teaching experience, but had been a foster parent. Based upon this experience the teacher coached other teachers in how to restrain my son.

It was during the Fall semester of his 2nd grade year (2007-2008), after the *Guidelines* were implemented in March 2007, we saw first-hand the use of restraint on Ike. I arrived to pick Ike up from school; the principal had suspended him, and the new special education teacher was beginning to restrain him in the main office. She took him to the floor and was on top of him while two other teachers were holding his arms to the ground. I watched this trying to think how I was going to get them off of him. I entered the fray and told them to release him to me. After the teachers moved back I was able to remove him from the situation, but it took more than 30 minutes to calm him. None of these teachers had any training in de-escalation strategies or how to safely restrain a child.

A second time, I arrived to pick him up from latch-key and, as was typical, Ike began to act out when a transition was taking place. The teacher in charge of the playground gave him a directive and he refused to comply. She immediately became authoritative and demanding in an attempt to get compliant behavior. I did not want to usurp her power in my son's eyes, so I backed up until the transfer could happen more smoothly. Regrettably, she sent him to stand against the school wall, where his behavior was being reinforced by the enjoyment of the power struggle. She did not recognize the dance that was happening, grabbed his hands and held him against the wall, with her knee between his legs. Again, I intervened and removed him from her care. This teacher, too, had no training in de-escalation strategies or safe restraints.

In the month of November 2007 we were told that the school personnel were restraining him multiple times a day. In all of these incidences no documentation was proffered or provided to us. None of these people wanted to harm Ike, but they were unprepared and knew of no other way to help him. His challenges are overwhelming and frustrating, but teacher frustration and not knowing what to do is no reason to restrain a child. In fact, in our view the use of restraint with a child is *failure to meet his needs*. Using restraint is an indicator of a poorly functioning educational system not aligned with its values of doing "what's best for children."

In December of 2007, Ike was transferred by the district from this regular education elementary school to a special education center for children labeled as Emotionally

Disturbed. We assumed the special education center staff was made up of highly trained special education behavioral experts. Ike became one of approximately 65 students over 90% of them male. The students were isolated from their typically developing peers 100% of their time in school; the special education center included three full-time security personnel who manned a large time-out room and, most worrisome to us, two seclusion rooms.

Within a month of being transferred to this special education center, Ike was being placed in seclusion without our knowledge and permission. Between the dates of January 22, 2008 and February 5, 2008 Ike was placed in the seclusion room *nine* times. On January 22, 2008 the school staff placed him in the seclusion room three times; He was secluded for five minutes, ten minutes, and seven minutes for a total of 22 minutes. On January 29, 2008 the school staff placed him in the seclusion room one time; He was secluded for seven minutes. On February 1, 2008 the school staff placed him in the seclusion room him three more times; He was secluded for five minutes, ten minutes and ten minutes for a total of 25 minutes. And finally, on February 5, 2008 the school staff placed him in the seclusion room two times. He was secluded for five minutes and ten minutes for a total of 15 minutes. Each of these seclusions was without our knowledge and without our consent. (Additionally, none of these seclusions would have been required to be included on any report submitted to KSDE because none of them rise to the arbitrary level of thirty minutes of seclusion.)

On February 5, 2008 the teacher-in-charge called us to ask what we recommended in order to change Ike's very disturbing behavior, since the seclusion was not changing his behavior. While Ike was in the isolation room, an older student was taunting Ike to misbehave, which Ike did. It was an especially busy time in the time out area and not enough staff was available to monitor the students in the time out room and in the seclusion rooms. These rooms were within the time out room and were open at the top so that all sounds carried throughout the room, defeating the purported purpose of providing no attention to negative behavior.

It was then that the teacher-in-charge informed us in an off-hand manner that he had been in seclusion multiple times already. We requested documentation for all of Ike's seclusions. We followed up with a written request. On February 7, 2008 (2 days later) we had not received the documentation and we requested a meeting with the principal. We presented a list of concerns, reiterating our request that seclusion not be used at all with Ike and again requested the documentation.

For several weeks the principal and other school personnel did not provide the requested documentation. When the principal provided the documentation, we were given a list of dates on which Ike was placed in seclusion and the amount of time and frequency with which he was there. We wanted to know what the antecedent behavior was for each incident and requested that information as well. It was not until March 26, 2008 that we received that information. It did not come from the principal as would be expected, but from a District Coordinator who had to request the information multiple times.

The 2008-2009 school year began in mid-August 2008. After only seven days of school Ike had been restrained at least five times. We were furious that his behavior, having been much improved over the summer, had deteriorated so rapidly at school. School personnel requested to use seclusion. We adamantly refused. In fact, we were considering whether to withdraw permission for restraining Ike as well. In late August

2008 the principal again requested to use seclusion as restraining had become reinforcing. We again declined to give our permission and were never given documentation as the *Guidelines* state.

In response, we met with the district's Due Process Officer, the Assistant Director of Special Education in charge of Curriculum, and the Special Education District Coordinator who was assigned to Ike's Special Education Center. Our discussion that day in late August 2008 centered on Seclusion and Restraint. Up until this month I had waivered in my certainty that I was opposed to seclusion. So, I began to research with a simple Google search. Within two hours I was convinced that seclusion and restraint no longer had the support of any of the major mental health organizations in the nation. Research articles reported about other special education centers in the nation that had been operating for 30 years without using seclusion and restraint. I was absolutely convinced within four hours that seclusion and restraint should only be tools of last resort for safety reasons. I could not find any research that said these tools were appropriate to use to modify behavior.

On September 4, 2008 we attended a scheduled meeting to develop a safety plan at school. The conversation was cordial, less antagonistic and more collaborative than before. Bart and I opened the door to the use of seclusion in an attempt to understand why the school wanted to use seclusion. What would it look like? Under what circumstances would seclusion be used? What kind of documentation would we receive? When and how would we receive it? We left the meeting with a positive feeling. We knew that we had begun to explore the idea with them, but had not given our permission to use the seclusion room.

After school that day we received an email from the principal telling us that she had placed Ike in the seclusion room twice that day for an unknown amount of time. She claimed that she somehow thought we had given our permission to proceed. All others at the table that morning reported we had not. That experience was the final action that finally and fully broke trust between the school and my family.

In December 2008, we presented written parental input to the IEP team, which, among other things, asked that the Kansas *Guidelines for the Use of Seclusion and Restraint on Children with Disabilities* be attached to Ike's IEP. We wanted to ensure that the special education center would now be legally bound to follow the guidelines.

By September of 2009 his behavior remained a challenge as we embarked upon a new therapeutic method, a Neuro-sequential Model of Treatment. At a meeting on September 29, 2009 the IEP team brought a proposal to the table that appeared to be a desperate plan. They requested that they be allowed to use seclusion with Ike the way they used it with all other students. They described the use of the seclusion room as a method to teach a student to calm down. Each time Ike hit, kicked, scratched, or threatened, he would be placed in the seclusion room. This would occur as often as necessary and as long as necessary until the seclusion changed Ike's behavior. We were appalled with this solution.

After this meeting we called the district's Director of Special Education and talked with him of our concerns and invited him to our IEP team meeting on October 12, 2009 to continue the discussion. We presented written parental input that expressed our considerable concern about this issue and how we thought the school should be responding. It was a long and contentious meeting, but ended shortly after the Director of Special Education clearly stated that the district would no longer be using seclusion and restraint as a behavior management tool. The only acceptable use would be in an emergency or crisis in which a student was so out of control and unable to calm, that their safety and the safety of others was in jeopardy.

With this clearly stated expectation the school began to change its practice. They developed a new decision-making protocol for determining when the seclusion room should be used. The protocol provided that it would take a team of at least three to seclude a student; a member of the Child Study Team (CST), a member of the security team, a staff member with knowledge of the situation, and ideally the principal. All team members must be in agreement that seclusion was appropriate. After a significant amount of training and discussion about the topic the school's practice has shown positive results. However high their use of seclusion had been before the 2010-2011 school year, it is now significantly lower. In fact the principal recently told us that since December of 2009 to January 1, 2011 the seclusion room had only been used ***two times*** and ***seclusion is no longer needed.***

This is indeed good news. However, this has only happened because a new principal has been pushing and pushing his personnel to behave in this way. What happens when this principal leaves? Or what happens if a new principal does not believe seclusion is not needed? There are no systems in place to incentivize other schools to make this happen. Because of these potentialities, the *Guidelines* remain, in fact, voluntary and up to the knowledge, skills, or whims of whoever is a school's leader.

The Kansas State Department of Education's PowerPoint, "Seclusion of Students with Disabilities: Year End Report 2008-2009" (found on the department's website) minimizes the extent of the problem of seclusion and restraint by reporting that only three-tenths of one percent of students in the state of Kansas were, that year, placed in seclusion.

Yet another perspective needs to be shown. The statistic .03% represents 950 living, breathing children who were secluded in that year. Additionally, the report does not show how many times each of these 950 students were secluded. Nor does it show what the ages of these children were. We cannot tell from the information requested of schools, if one individual is responsible for the decision to seclude or restrain or if it is a team that includes multiple voices and areas of expertise. Seclusion experiences that last less than 30 minutes are not even reported. These are but a few of the questions raised by the limitations of the data required to be reported.

An important revision that should be included in the codified version these guidelines is removing the implication that seclusion and restraint are tools to be used to change behavior. The only appropriate time for the use of seclusion or restraint is when they are the tool of last resort; all team members making this decision are agreed that every other possible avenue has been fully examined; it is a crisis or emergency; and that seclusion and restraint are used to protect the safety of the student and of others in danger. Never should it be used to try to change behavior. Only in the direst of circumstances should students meet this fate.

As so many mental health organizations advocate, "*The use of seclusion and restraint is treatment failure!*" As such, Bart and I urge this committee to revise the state guidelines on seclusion and restraint and turn them into law.

Thank you.

Kris A. Ehling

STATEMENT
LEE STICKLE
KANSAS STATE DEPARTMENT OF EDUCATION

Hello, my name is Lee Stickle and I work on one of the statewide projects funded through KSDE. I have been an advocate for the rights of children, those with disabilities and those without for my entire professional career. As you consider the issues presented today, I would ask that you keep in the forefront of your mind that the issue being considered is not one of holding adults responsible after an incident, rather our job is to build the capacity of adults to significantly reduce the number of times seclusion and restraint is used. Regulation of the use of seclusion and restraint is at best reactive. Our purpose should be to provide adults with the tools they need to more effectively manage the behavior of children. Teachers, parents and care providers should never be in a situation where the only option is to place their hands on a child. Through training and local leadership, we can develop additional behavior management skills; those skills can reduce the number of times seclusion and restraint is the intervention used. Regulation will not impart skills to the adults and regulation will not stop the abuse of children; we have existing laws, regulations and guidelines to protect the child. It is changing the behavior of the adults that will make the difference in the lives of kids. Perhaps if we can take the collective energy, resources and passions of those who care about kids, we can make a lasting change in the way that we communicate and interact with them.

Nothing is more destructive of respect for the government and the law of the land than passing laws which cannot be enforced.
Albert Einstein

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Northwest Kansas Educational Service Center
703 W. 2nd Avenue
Oakley, Kansas 67748
(785) 672-3125

House Committee on Children and Families

Testimony on Seclusion and Restraint

February 10, 2011

Submitted by
Katherine Kersenbrock-Ostmeyer
Director, Special Education and parent of a recent special education student graduate

Honorable members of the House Children and Families Committee,

The topic of seclusion and restraint has become a very personal issue for me---not as the Director of Special Education but as the parent of a child who was in need of some pretty intense behavioral intervention during his middle school years. During that time my son exhibited as part of his Tourette Syndrome (co-occurring with Attention Deficit Hyperactive Disorder) numerous incidence of what some would label a rage reaction. Similar to a tic, these incidences came on rapidly and were not something well controlled. Although the school experienced far less of the behavioral outburst than we did at home—these incidents were the types of violence that every parent fears in which the child could strike out physically and verbally to an extent that most adults would become fearful for their own safety. Luckily our son's school was diligent in developing a Behavior Intervention Plan (BIP) which was used as a safety procedure to help him effectively deal with his outbursts as well as serve to secure him in situations where he was at risk of hurting others or himself.

I am pleased my son's school and his IEP team had an option to implement a program/plan that allowed a seclusion option. As a long time special educator and administrator I can pretty much guarantee that without these options during that volatile period in my sons life--the school would have had very little option to provide a different type of intervention other than calling law enforcement, or requiring he attend some alternate program. As both a parent and a special educator I believe that the best place for my son was in his hometown school educated with his classmates.

In Kansas, we are in the forefront when it comes to addressing seclusion and restraint guidance. When researching this topic I found that Kansas is one of only a few states requiring training of administrators and staff in the implementing of seclusion and restraint. Since the current guidelines went into effect KSDE has not received parental complaints or found a situation where a school was abusing the seclusion or restraint guidelines. Furthermore when I discussed

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this issue recently with other special education directors I was told---that of the stories shared in a recent Disabilities Rights PowerPoint, none of those incidence have come to them for investigation in recent years.

The guidelines are working and individual special education teams are currently able to develop plans to best meet the needs of students. When schools or any business or organization have additional regulations imposed on them—one of two things usually happens: 1) they get out of the business for fear of legal situations and risk (not an option for public schools); or 2) they becomes overly cautious and restrict activity to prevent any chance for a violation. For schools I fear (and have already heard) in order to avoid risk situations special education teams will avoid any type of seclusion or restraint and simply call law enforcement. For children like my son this would have been life altering as he had enough issues without experiencing criminal charges.

In conclusion, I would also ask that as you address the issues of seclusion and restraint the following items be reviewed:

- Federal guidance is currently being explored in the legislature. It could be in Kansas's best interest to wait and see what becomes regulated at that level before adding new state laws; and
- In addressing seclusion and restraint why are we only looking at the special education arena---shouldn't any student fall under current guidelines?

Thank you for considering my concerns surrounding this issue,

Katherine Kersenbrock-Ostmeyer
Parent of a child with a disability (who just graduated from Colby High School in December and is preparing for Vocational School next fall), and Director Special Education Northwest Kansas Educational Service Center

Special Services Cooperative
of Wamego

USD # 323 Rock Creek Valley
USD #320 Wamego
USD #329 Mill Creek

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Mike Bilderback, Director
Diana Phillips, Office Manager

February 7, 2011

Re: Seclusion/Restraint Hearing

Dear Chairperson, and Members of the Kansas House Children and Families Committee,

My name is Mike Bilderback and I am the Director of the Special Services Cooperative of Wamego as well as an Executive Board Member for Kansas Association of Special Education Administrators (KASEA) and Chairperson for Region 2.

I want to be clear about who I am representing today. I speak to all of you as a single Director of Special Education rather than as the spokes person for Region 2. With the weather conditions handed to all of us I was unable to gather any group/regional consensus on this topic. Should other open hearings be held on this topic it will give me time to further inquire with colleagues in Region 2 and then offer group consensus comments on this topic.

For background purposes, our Cooperative involves 3 school districts, and 13 buildings covering 2 counties. Over the past 13 years we have averaged 417 students in SPED services and are considered to be an "average" sized Cooperative in Kansas.

I do not endorse the need to establish a Kansas regulation for the use of restraint in our schools. I base my decision on the following facts.

- There is no IDEA standard, or other Federal regulation for restraint, and until this is placed into regulation at the Federal level then I do not feel that such should be voluntarily established in Kansas. Directors across Kansas are already facing over 1,000 laws and regulations associated with Special Education Services.
- KSDE, approximately 5 years ago, established guidelines for both seclusion and restraint and established quarterly reporting periods from all school buildings regarding the number of seclusions and pertinent information related. Even if a building has no seclusion events within a single reporting quarter, the building principal is still responsible for reporting zero incidences, therefore all building should be reporting quarterly. KSDE summarizes all data collected and this is available on their web-site.
- To create a separate reporting system for restraint will double this reporting workload of every building principal in every building across Kansas.

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- According to data on the KSDE website, only 217 students with Disabilities were secluded during the first quarter of the 09-10 school year when divided by the Dec. 1, 2009 child count of 55,518 students resulted in .4% (less than 1% of all the students served). This is not intended to diminish the use of seclusion, but it does place into perspective the extremely limited number of such events over a 45 day period. More telling is that if 217 incidences occur in an 45 day period then this represents 4.8 incidences per day in the 1380 public schools in Kansas.
- Most, if not all, schools and SPED organization have policy/practice guidelines on seclusion and restraint, conduct annual in-service on these topics and keep local data. For example, all seclusions within our Cooperative are reported on a special form, sent to my office, and then sent to our NCI restraint trainer to ensure that the proper steps were taken given the situations students present.
- Most, if not all, schools sponsor annual restraint training events for both regular education staff, administrators and SPED staff. These training are for new staff as well as returning staff needing re-certification. Our Cooperative sends our NCI trainer for re-certification as directed by the NCI organization. For example, our Cooperative will provide 7 different training events this year (and do so within a 9 month calendar), as well as sending our NCI trainer for re-certification this year. We purchase the training booklets that NCI encourages and use these at all training events.
- In addition to local in-service efforts there are also regional in-service opportunities on pertinent topics such as functional behavior assessments, and Integrated Positive Behavior Supports (IPBS), as well as the new MTSS model being endorsed by KSDE.
- Restraint and seclusion practices are disclosed to every parent at every IEP meeting where instructional staff feel that such an intervention may be needed during the course of the year. The locations of restraint rooms are available for parents to visit, and those trained are identified.
- When seclusion or restraint is used our SPED teachers and building administrators report this to our parents within 24 hrs.(and more times than not prior to the end of the school day).
- Given the facts stated herein our Cooperative has not had one single child complaint, or due process hearing filed nor one single phone call to this Directors office suggesting: over usage, improper usage, improper judgment on staff's part, or a general complaint since the inception of the KSDE guidelines.

Unless a number of child complaints have been filed with KSDE or due process hearings (within recent months or over the past 4 years) suggesting school negligence then I question why KSDE should consider exercising a regulation when there is no Federal regulation.

Thank you for your time. I am always available for additional comment or questions.

Submitted by,

Mike Bilderback

Cc: Region 2 Directors
Linda Aldridge, Region 2 Legislative Spokesperson
Superintendents of the Special Services Cooperative of Wamego

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Families Together, Inc.

Parent Training & Information Centers for Kansas

Home Page:
http//www.familiestogetherinc.org

Wichita Parent &
Administrative Center
3033 W. 2nd, Suite 106
Wichita, KS 67203
Voice/TDD (316) 945-7747
1-888-815-6364
Fax (316) 945-7795
wichita@familiestogetherinc.org

Topeka Parent Center
501 Jackson, Suite 400
Topeka, KS 66603
Voice/TDD (785) 233-4777
1-800-264-6343
Fax (785) 233-4787
topeka@familiestogetherinc.org

Garden City Parent Center
1518 Taylor Plaza
Garden City, KS 67846
Voice/TDD (620) 276-6364
1-888-820-6364
Espanol (620) 276-2380
Fax (620) 276-3488
gardencity@familiestogetherinc.org

Kansas City Parent Center
1333 Meadowlark Ln., Suite 103
Kansas City, KS 66102
Voice/TDD (913) 287-1970
1-877-499-5369
Fax (913) 287-1972
kansascity@familiestogethinc.org

Statewide Spanish Parent Line
1-800-499-9443

February 10, 2011

Representative Kiegerl and members of the Children and Families Committee:

Thank you for the opportunity to provide testimony today. I represent Families Together, Inc. a non-profit organization which serves Kansas families who have children with disabilities or special health care needs. It is our mission to encourage, educate and empower families and their sons and daughters with disabilities to be effective advocates. We currently are the recipients of the Parent Training and Information Center grant from the Federal Department of Education to assist families in understanding and navigating the Special Education system, and the Family to Family Health Information Center grant to assist families of children and youth with special health care needs to find their way through the maze of health care. In addition, we also have contracts with Social and Rehabilitation Services, Kansas Department of Health and Environment, and the Kansas Department of Education to help each of those agencies serve families of children with disabilities or special health care needs.

Families Together has centers located in Topeka, Wichita, Garden City, and Kansas City. All of the offices are staffed by parents and/or education advocates of students with disabilities. Every day we talk with parents across Kansas regarding school issues. Over the past several years we have experienced a continual increase in the number of parents calling for assistance related to behavior or discipline concerns at school.

By now you have heard a lot of testimony on this issue and have been given thorough information related to the process and timeline that has brought us to today's discussion. Rather than repeating much of what you've already heard, I'd like to you give you an account of my personal involvement in the events around the topic of seclusion and restraint and Families Together's position.

When a bill was first put forth in 2005 Families Together worked collaboratively with DRC and Keys for Networking to get information out to families and to offer them an opportunity to share their stories about the use of seclusion and restraint for their children. The response was larger than we anticipated and many parents tol

Assisting Parents and Their Sons and Dau

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members of the legislature. The Senate Education Committee asked the Kansas State Department of Education (KSDE) to develop policies on the use of seclusion and restraint and to conduct a survey regarding the use of seclusionary "time-out" rooms or areas. Families Together worked collaboratively with KSDE to get this survey out to parents and special education directors across the state in order for KSDE staff to have as much information as possible regarding current practices as they prepared to establish guidelines and/or regulations about the use of seclusion. Stakeholders including representatives from KSDE, Families Together, DRC, Keys for Networking, Project Stay, and Kansas Association of Special Education Directors came together for discussion and to offer suggestions about what should be included in the guidance from KSDE. The group not only worked hard but they worked together well.

In 2007 when the Kansas State Board of Education (KSBE) held public hearings and grappled with the hard decision of whether or not to adopt guidelines or move forward with regulations, families once again came out to share their stories. I need to stress that these are not easy stories to share. It takes a lot of courage for a family to stand before strangers and bare their souls on such a sensitive issue. There was a lot of discussion among the state board members that day. I believe they listened intently and truly recognized the enormity of the concerns that were brought to them. I have the utmost respect for Rod Bieker (Legal Counsel for KSDE at the time) for the tremendous amount of work he put into drafting regulations that set forth reasonable standards that adequately addressed the concerns and interests of all – including students, parents, teachers, and administrators. At the end of the day, however, KSBE chose to go with guidelines instead of regulations. They did so after considerable discussion about school districts allowing for the guidelines to be attached to a student's Individualized Education Program (IEP) when appropriate; thus, making the guidelines enforceable and giving parents an assurance that they would be notified of and involved in how the use of seclusion and/or restraint would be used with their children.

In the years since the guidelines were adopted much has been accomplished. KSDE staff members have collected and reported on data about the use of seclusion and offered a great deal of training to local districts on how to accurately report the data and follow the established guidelines. Unfortunately, we continue to hear stories of the misuse/abuse of the use of seclusion and restraint in Kansas schools and about schools who refuse to attach the guidelines to IEPs. No, we do not hear from droves of families but we continue to believe that it is inexcusable to allow even ONE child to be subjected to the misuse of such interventions. And that it is equally wrong to place school staff in a position to use these techniques without proper training and full disclosure to the parents or legal guardians of these students.

Given the climate of today's schools, the number of students with behavioral and developmental challenges, and the increased awareness about this issue across the nation, we believe enforceable standards make good sense.

Please feel free to contact me if you need any clarification or if I can be of additional help.

Respectfully,

Lesli Girard

Lesli Girard, Program Director

My name is Aimee Keohane and I am a parent of child with Autism. My son school began in the Gardner-Edgerton School district in pre-school in the 2003-2004 school year, he was 4 years old. Connor was, at this time, on the wait list to be tested for Autism. Connor was enrolled in the districts "Communication Classroom" which is, according to the district, for children on the Spectrum. In April of 2004 we reviewed Connor's IEP and the entire team agreed that seclusion and/or restraint were not necessary for Connor. Connor continues with his extended school and goes on to resume school for the 2004-2005 school year. It was written in his IEP that he would attend Kindergarten in the first half of the day and the "Communications Classroom" the second half of the day. As the first weeks progressed, I was given daily notices with "Smiley Faces" indicating Connor had a good day. I had concerns because I noticed that Connor appeared to be regressing. During a fall evening I was attending my daughter's play at the school and I happen to walk by the "Communications Classroom" for students with Autism and noticed a wooden box referred to later as the "Safe Room". I asked what the wooden box was and I was told that was one of the school's safe rooms. This was also around the time parent/teacher conferences took place and I met with Connor's Kindergarten teacher and the Communications Room teacher. I was told that Connor was meeting all of his goals including his behavior goals. I asked if Connor was ever put into the safe room for behaviors and the meeting was ended and I was told that they didn't have time to address that issue.

Following this meeting I went to administration building and request copies of my son's files. The secretary complied and made copies while I waited. I was attempting to leave the building when I saw the Director of Special Education. She walked up to me and told me that I couldn't have the copies and forcefully removed them from my hands.

It wasn't until I hired an attorney was I able to have access to all of my son's files. During this process it was discovered that my son was secluded in the safe room 87 times and up to 6 times a day from the first weeks of school through October of the 2004-2005 school year. I immediately wrote a letter to the Principal that this was not part of my son's IEP and the use of the safe room and seclusion was to be stopped immediately. She agreed, however the week went on and the Friday of that week the Director of Special Education called and left a message on my answering machine that my son was secluded several more times.

After watching my son regress I took him to Kansas University for help. After all the seclusions he was also diagnosed in addition to Autism, Post Traumatic Stress Disorder, and Generalized Anxiety Disorder. After explaining to the Kansas University Doctors what my son had been through they collaborated and all of them wrote letters to the school explaining that the use of seclusion or restraint is detrimental to my son's health and to see alternative measures. However the school continued to seclude him.

At this point I couldn't get my son to walk through the front doors of the school. The school agreed that he was traumatized and agreed to home bound services for the remainder of the school year.

When school resumed for the 2005-2006 year, the school refused homebound services and wanted my son back in school and wanted to continue the use the safe room. I refused. We had several meeting with attorneys and we disagreed about seclusion and restraint. My attorney filed papers for due process.

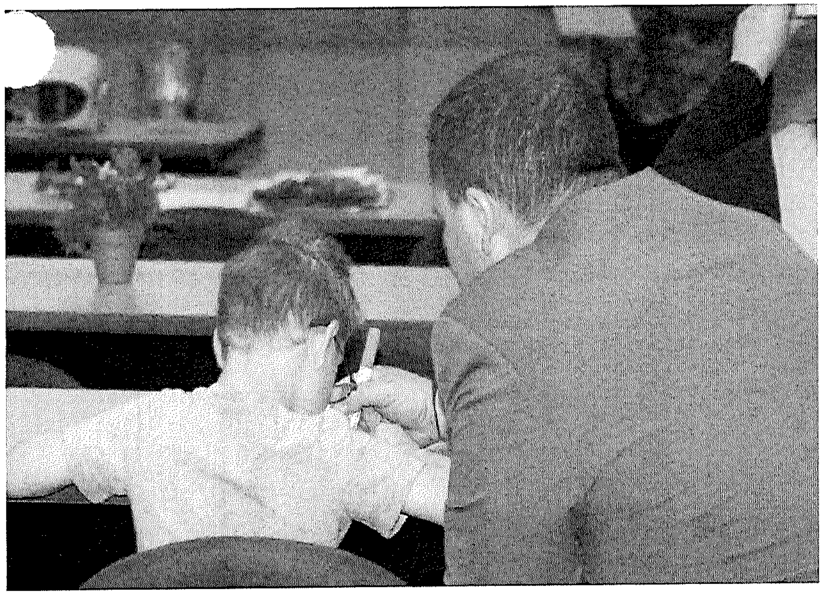
(over)

It was then that the district retaliated and reported me to SRS as a negligent parent. The charges were dropped and the appointed attorney wanted to pursue legal against the school because what the documentation revealed. We decided we were too emotionally and financially exhausted to continue with any more legal action.

In IEP meetings post 2007 the district has requested to add restraint to my son's IEP. I was told that they cared more about my son and they were advocating for my son more than I was because restraint would protect him. When I refused I was told that they (the district) would have him arrested if there were any type of incident. I further asked to have the Seclusion and Restraint recommendations attached to his IEP and the school refused giving this response: "We have a policy in place that applies to the entire district; therefore it all applies to all students, including Connor". The school also tried to force the wording on my son's IEP that I have read and completely understood the school's policies. I again refused.

The question was asked "why don't parent file a complaint or go to due process over this issue?" As one of those parents I will tell you why. I had accumulated nearly $45,000 in attorney's fees, the school retaliated by reporting me to SRS, the emotional drain is beyond anyone's understanding, and most importantly there are no regulations on seclusion and restraint in the Kansas public education system.

I am only asking for clarity. Regulation on Seclusion and Restraint is necessary in order to protect our children and our schools, as well as having the parent and the Board of Education informed of the true data of what seclusion and restraint looks like in our schools.



Dylan
Banning
1st Grade

Following the directions for the gingerbread man picture assignment, Dylan drew eyes and a smile, then came to #3 which states: Draw 4 buttons on the Gingerbread man's shirt. Dylan asks, "Where the heck is his shirt?"

:cember 14, 2010

Three weeks after school started, we received a phone call informing us that our attendance was requested at an IEP meeting. Understanding that this was not an annual meeting, we asked the purpose of the meeting and was informed by the special education teacher that the SPED 618 policy on the use of seclusion was to conduct a meeting following the incident. Dumbfounded, we asked when the "incident" had occurred. We were informed it had happened on Wednesday—this was Friday! Dylan's behaviors had escalated throughout the day leading up to seclusion and he had been sent to a time-out area by the school principal where the meltdown continued.

Instantly realizing the incident explained some of Dylan's other behaviors that week including bedwetting and crying at the morning drop off at school, we politely relayed to the special education teacher that seclusion is absolutely not an option for our child, we would waive the 10 day notice and wanted the meeting immediately. Supported by the 9 pages of guidelines set forth by KSDE, we'd hoped to have attached to Dylan's IEP, we were shocked to find that our SPED had instituted their own guidelines, consisting only of a page and a half and thus there was no need for the state's.

This incident is the first and only issue of seclusion that we, as Dylan's parents, have been made aware of. Dylan is an amazing and gifted boy, he has Asperger's Syndrome and often the first several weeks of school are what some call a honeymoon, where he learns about his surroundings and processes everything. At home, we have few behaviors and are able to "get a grip" so to speak on his behaviors before they escalate. While we understand that Dylan can be disruptive to the class, a simple break to the hallway often helps him process. Secluding him to an area and forcing him to stay there will only fuel the fire.

We want to take this moment of your time to reflect on two topics:

- If Dylan was forced to stay in his room, or as parents we physically restrained him for long periods of time, an investigation by Social and Rehabilitation Services would be warranted.
- There was no timely report in our incident. Dylan had given us clues as to an incident occurring at school, through other behaviors, but no documentation was given to us.

We charge this committee to set forth the guidelines on seclusion and restraint recommended by KSDE as regulations. School shouldn't be a place of fear.

Respectfully submitted,
Jeremy and Rachel Banning
Kansas Senate District 25 and House District 105

The following email was sent to our Families Together, Inc. office in Wichita on February 12, 2010 from a grandmother. She has requested her testimony omit her name, her son and grandson's names and any details in regards to devulging location of hometown whereabouts as they have since resolved the issue by changing schools, however, their residence is still in the small town.

I am writing to ask for help for my grandson, R . He attends P Elementary in , KS as a second grade student. Presently, he is receiving one-one services in an 8' x 8' room with no windows. He eats lunch alone, has recess alone, and has his inclusion time that is on his IEP taken away for behaviors earlier in the day or even the day before. He is shunned by students with even the para saying that students will not say, "Hi." I am certain that his behavior has caused much difficulty. He is a paradox as his behavior here, while not totally angelic, is definitely not problematic in group situations such as swim lesson, group play, neighbor's homes, and Sunday School whether structured or not. His father feels that he best not say anything as things could get worse. When we share that there are not problems here. it is not heard or even discounted as not true. It can be proved that he does well here. R has cried when telling me about the isolation. I am not feeling that this degree of isolation is in his best interest or is the Least Restrictive Environment. I was told that R had told them that I would "take care of this", but the truth is that I did not even know that a meeting was being held until the day before the meeting. At the meeting, I was told that they told R l, "WE are not scared." I even feel intimidated to say anything. I am sure that R thinks grandma will "take care of things" that are happening that are wrong, and I feel helpless that this is going on in front of me. I am sure that the school believes they are doing the right thing, but I do not think the degree of isolation that has taken place is appropriate. It is basically like being in jail or in school suspension without benefit of good practice on doing well. He has no interaction with peers on any level - not even coming and going. He was punished for correcting two boys who peaked in the girls' bathroom which I agree was none of his business. The general education teacher said she would not put any of her students with R l as she has notes from some parents that their child should not be around R . This was to simply play in a supervised way one on one for a recess time. This was very disconcerting to R l's father as R 's needs were not being considered. I feel they are making him the community outcast, and the situation is worsening by the day. I would certainly think that he should not be having his inclusion time taken away from him which has been very successful even though even there they have him sit on a rug a little away from the other children. He has become the pariah of this little town. This is a small town and they say he is too high functioning to receive services in the resource room as he might bully with comments some of the other students. I would think that his one-one para would be able to handle that. His father, A , has taken a picture or R 's room at the school. He is scared to say anything anymore. His phone number is 785- - . If this information needs to go elsewhere, please let me know. I do hope that it will be looked into for appropriateness and least restrictive compliance. I am simply asking for more inclusion in an environment that is more healthy. I did speak up at the meeting and ask that he at least have lunch with a student buddy. It was said that it would be looked into. When I asked about the IEP time being taken away, it was said that he is fully cognizant when it is being taken away that it is in response to his behavior. It was admitted that he very badly wanted more time with his peers. When my grandson cries to me that he is hurting, I feel a need to at least ask that the matter be looked into very carefully. Truthfully, I am extremely concerned that the communication with the school will worsen with contacting you, but I feel that I could not stand by without asking someone to look more fully into the matter. Please do not think that I am simply a doting grandmother. I have a masters in special education and taught emotionally disturbed th grade for several years. I have never seen anything quite like this, and I am struggling to believe that this is happening. However, I am at a loss as to what I can do. Please give some insight on this matter.

T .NSAS LEGISLATORS AND KANSAS BOARD OF EDUCATION

My name is Leann Sumpter. This is in concern about how seclusion rooms are being used and the effect it has on our children. I know how it affected my grandson. I have adopted him and his sister. They were in five foster homes in the ten days that it took for us to get our KBI background check done. They had a rough time before going into the system. We have had them in our home since AJ was two years old and his sister was one.

Anthony, who goes by "AJ", started kindergarten at Chase Co. USD #284. AJ has asthma and other health problems and has had a lot of behavior problems, with eight incidences of aggression. In his kindergarten year, through an IEP, he received special education services and a para with him for most of the day. He began therapy and was put on medication. At that time, he was diagnosed with ADHD, RAD, ODD and Pervasive Development Disorder with a history of physical, mental and sexual abuse. Later on, post traumatic stress disorder and anxiety disorder were added. By the end of kindergarten, he did not have any aggression but still had behavior issues. IEP members decided that when he started first grade, he would start a Connection program that was at Logan Avenue in Lyon Co. Dist. #253. I was concerned within a couple of weeks about what they called the "time-out room." He would come home with the toes of his shoes torn up from kicking the wall. His fingernails were broken from picking off drywall in the room. I took a lot of notice at this time and saw that he was being put in there for things such as not following directions, antagonizing the teacher and walking around refusing to work. Once, he was even put in the time-out room for passing gas. The teacher told me that kids with disabilities can do this on purpose. I thought they knew best about what to do for him. These were supposed to be highly educated teachers. (This is what I was told every time I questioned them.) There was a class ratio of six students to five or six staff in one room. By the end of the first year, I was very concerned. His behaviors were getting more aggressive towards the teachers and staff at school and he was becoming frightened to be in a room by himself at home. He was having nightmares from time to time and was telling me that when he was in that room by himself he would be afraid that robots or something was going to get him, so sleep started getting hard and he was up and down throughout the night. Then he would sleep at school. I called for lots of meetings. I looked up the Kansas guidelines for restraint and seclusion. I talked to Cammy at the Chase Co. Board of Education, the principal at Connections, the principal at Chase Co., where he was actually enrolled and Mrs. McCoy, the Director of Special Education. I asked why, if he's not an immediate danger, he was being put in this room. We had several meetings where I was told that they put him in before it escalated. I then questioned the length of time that he was kept in this room. I was getting nowhere, and by this time AJ was becoming very aggressive at school with the teachers (never with the other students). He was hitting and kicking the teachers. He was coming home with bumps on his head from hitting his head on the wall, scratches and a couple of bruises to his forehead. He was damaging school property so I called The Farm, which is the agency I went through to adopt the kids. They gave me Families Together number to find help on IEP papers, so I called Kayzy and faxed her some of the behavior and time-out sheets. There were times when AJ was in the time-out room for one to two hours. He urinated on himself while being confined in the room, he slept in there and ate lunch in there. I questioned why, when after it said he was calm, he had to stay. I was told that he had to sit on the floor quietly for five minutes after he was calm before he would be allowed out of the room. They had a timer. We had a couple meetings got a few things settled, and by then it was the end of the school year. Second grade stared pretty well but then the same things started again. I sent a "no consent" letter via e-mail to the state. I did not consent to putting AJ in the timeout room. This did nothing. I then took AJ to see his pediatrician, Dr. Brown. He wrote a letter to the school on April 22, 2010 stating that AJ had numerous health and behavior problems, including asthma and that it could be a risk to him mentally and physically and that keeping him in this room isolated from other children did not seem appropriate and at times may be detrimental. If it would worsen his current health conditions the anxiety could trigger his asthma. The letter went into more detail as to what could happen. Principal Giffen said that they did not have to go by a doctor's recommendation. I was getting time-out sheets which stated that he was eating lunch in this room again. He had also urinated on himself in there a couple of times. We had a meeting with Kayzy from Families Together and I asked that the Kansas restraint and seclusion guidelines be attached to his IEP. The principal, Mr. Giffen, said that this was unnecessary because they all knew the law. Kayzy explained that it was for their protection as well as AJs. Mrs. McCoy, the Director

(over)

of Special Education, said that she would have to talk to the school's attorney and get back with us. She never got back with us. Through all of this, AJ's anxiety about being in this room by himself got worse. We could not shut the bathroom door if he was in there. I had to stand outside the open door for baths and while he used the bathroom. School got worse for him. Things were getting very bad for AJ. He was always sad and crying. On October 1, 2010, AJ threw a rubber apple at a marker board. He refused to work, was yelling and then hit his head on a computer, so they put him in the timeout room. The school called Kristy Hatfield, AJs crisis manager. I don't know what the school told her but she called the police and headed to school. She then called me. He was asleep on the time-out room floor when police and Kristy arrived, so police woke him up, handcuffed my seven year old boy and walked him though the school. I then met them at the Mental Health facility where he received emergency services. It was decided by me and the mental health staff to have him hospitalized at Marillac in Kansas City. He was there for five days. While there, they added post traumatic stress disorder to his list of disabilities. When I told them about the time-out room they said this would cause him to be aggressive because, with PTSD, he would fight if backed into a corner. He received a lot of medication changes. I then told the school "NO MORE shutting the door on him and for sure no more cops and handcuffs". He kept making statements that police were bad. Before this, all he talked about was becoming a cop. He said "I thought they only handcuffed bad guys. I wasn't bad, Grandma. I was just tired so I fell asleep." He was very confused for awhile and when he returned to school, we decided that they would call my mom instead of putting him in the time-out room, since she lives blocks away and I live 28 miles. The calls were almost daily. We went to Emergency Services at a mental health facility a lot. After one of those times, AJ was suspended so I went to school to pick up his stuff. The school psychiatrist said I needed to have him hospitalized in a residential hospital for long term - at least a month or two. I said that the mental health staff and I didn't think that was necessary. He was only in fight mode while in there. She then said "If you don't it will be out of your hands in three days." Later, Social Services was at my door to investigate a complaint of neglect saying that I was being accused of letting AJ hurt us and himself and that I was getting no help for him. I gave them all of AJs support people's names- therapists, case manager, crisis manager, medical clinic and doctor. I signed all the releases. Of course the complaint came back unfounded. He received all services available to him and he didn't hit his head on walls, leaving bumps, or hit or kick us. At school chaos continued. AJ was having great difficulties and was sent home more than he was at school. They said this was not a suspension since it was my wish to have him leave instead of being in the time-out room. He continued to cry a lot at home and was still very scared to be in a room by himself so I called the Disability Right people and asked what my options were. The only one that would get him out of there was homebound services so I requested that and on November 14, 2010 we started.

It has been great. He has never hit or kicked the teachers. He's had a few episodes of refusing to work, but most days he gets 100 percent. After the first week he said that he did not know teachers could be nice. He now talks about what he's learning and is excited to show me things he's done in school. A whole new AJ! Of course we still have our bad days and I'm sure this will continue. In one and a half years at Connections, he never got a 100 percent on behaviors. He is starting to go into rooms by himself a little at a time. We still have times he won't but I can, most of the time, leave a room now without him screaming in terror and no more bumps and bruises. I could not write in here everything that we have been through or all the incidents of the last year and a half but I can tell you that I hope soon no other child has to endure this. The IEP staff has discussed reintegrating him back into Connections. I talked to him and he said "Please Grandma, no! I have been good. I don't hit. Why would I have to go back there? I can't take it if they put me in that time-out room. I can't do it anymore." I saw the fear in his face and the tears in his eyes. I knew I had to try to keep him out of there. The teacher doing homebound discussed this with AJ too and got the same response that I did, so at the meeting the other day the teacher from homebound requested we reintegrate back into Chase Co. with her help taking baby steps a couple hours at a time. I don't know what would have happened to AJ if I would have let this continue. If, like so many parents, I would have continued to think they knew what was best for him he may have someday been one of the sad stories we read about - a child dying alone in a jail cell-like room. It needs to stop. If a parent were to treat their child like that they would be charged with abuse. Why do we let our schools do this to them? Its neglect, its mental abuse and usually done to children who already have mental challenges. I pray that this stops soon.

TO: Kansas Legislature

DATE: February 8, 2010
SUBJECT: Seclusion

My son, Ty Greene is a kindergartner who attends Wanamaker Elementary in the USD 437 school district. Ty is a vibrant 6 year old boy who has Autism. Ty has attended the special education program with USD 437 since he was three years old. During the first semester of the 2010-2011 school year, Ty's behavior had gotten worse. Ty would use his behavior to destroy the classroom, or to harm a staff member at Wanamaker Elementary in hopes to get out of doing a task.

In January of 2011 the school asked my permission to have Project STAY come and evaluate Ty's behavior. Project STAY suggested using seclusion as a means to let Ty know that he cannot attack staff members and he cannot destroy a classroom or get out of a task. Project STAY also noted that a lot of Ty's behavior was attention seeking. I must admit that at first I was not too comfortable with this suggestion. Therefore, I contacted Families Together to get advice on seclusion and to find out my rights as a parent. I also contacted my son's Autism Consultant with the Autism Waiver to get her advice and she also attended my meetings as support. After doing some research and sitting down with what I like to call, my team of advisors, I decided to be up front and honest with the school about my concerns. I also shared with them all the information that I learned regarding seclusion. When I talk with the staff at Wanamaker Elementary they were very understanding and worked with me to come up with a Behavioral Plan that would ensure that I felt comfortable about Ty being secluded. For instance, every 45-60 seconds the teacher would open the door to "Ty's office" and say, "Ty, quiet hands, sit in green square," and during this whole process data would be taken. At that meeting we discussed training that would take place with the staff, my rights, data that would be taken to ensure that the seclusion was being done correctly, and to implement transitions when improvement was made. We also laid out guidelines on when the door would be shut to the seclusion room and when it wouldn't. The school also allowed me to use a teacher that I trusted to implement the new behavior plan and oversee the other staff members. At this meeting a new IEP was drawn up with the new Behavioral Plan that we agreed on as a team.

Since that meeting, the staff at Wanamaker Elementary has become a part of my family. The data and support they have given me during the process has been outstanding. The best part to this whole method is that it is working for Ty. Ty has picked up on the new method so quickly and he is learning how to respect his environment and the workers working with him. They rarely have to seclude Ty and when they do, it's only for seconds at a time. We are already transitioning to other steps. I have gotten outstanding data and there has even been video footage of how the seclusion has worked for Ty. I am now a personal believer that if seclusion is done "correctly" it can work. Parents just need to know their rights, and schools need to be trained on the proper way to do seclusion and on how to be held accountable for their actions. The most important factor is, parents and schools need to be a team. You need to trust each other and build a bond to better ensure the child's education.

If you have any questions or would like to see any documentation I may have please feel free to contact me at the information below.

Sincerely,

Jessica B Greene

3404 SW Shunga View CT
Topeka, KS 66610-1499
(785) 383-8479
jbggreene@att.net

9-10

I am sending my comments on seclusion and restraint in school. I have a 19 year old son with autism, seclusion and restraint only escalated his behavior. It was like adding gasoline to a fire. There was over use of this procedure instead of following behavior plans. If the school personal had been trained n autism and to ignore behaviors and to not cause the escalation of behaviors the need for this type of punishment would not be necessary. At South West Junior High in Lawrence at the first refusal of working they would put my son in seclusion which triggered his fight or flight instinct. If he had not been moved to the little room and ignored he would regain his composure and be able to finish the activity.

My son has come home with bruising on his abdomen, neck, arms, legs and cheek. He was punched, choked, dragged down the wall in order to get him in a time out room. When asked they said he caused all these problems by resisting. He still calls SW Jr. high SW prison, and has said over and over again they treat me like I'm a prisoner there.

If we were treated like he has been in the past at school we would fight for our life, just like he was. He said they are trying to kill me. I have reported this numerous time only to get the response of he gets aggressive. We don't know what to do.

LInda Weinmaster
lawrence
785-843-4060

9-18

Ladies and Gentleman of Legislature,

As I sit here and write this letter, I am overwhelmed by the fact that I will be limited in what information I can provide. My son has been subjected to seclusion and restraint in our area since he was in pre-school. I do not think it is easy to be able to show the negative in-pack that this has on the lives of the young ones that are subjected to its' cruelty or to the family that is given the brunt of its results.

My Son, who is currently 8 years old, is a wonderful, vibrant child. He loves to meet people, and loves to please those around him. My son was diagnosed with ADHD at a very young age. With that, he is very impulsive. He also has a hard time sitting still for long periods of time. His principle describes him as a "ball of energy." As a child, he did not know how to exert his energy, or anger. When he began pre-school, his teachers would set him apart from his classmates on numerous occasions. It did not matter if he was just a little squirmy during circle time, or if he needed to be elsewhere due to being upset. He was isolated during nap time as well. During a parent teacher's conference, one of the instructors noted how the children were isolating my son in the classroom, and I asked her if it could be because the teachers are isolating him from the class so much, and the children see that. She could not answer this question.

As my son got older, he went though kindergarten, first, and now is in second grade. I cannot describe all of the times that he has been restrained. I will describe one issue that occurred this year. It happened shortly after the school year began. When my son comes home from school, and I come in from work, we have a routine where I ask him how his day is and what he learned. He is older now, and so he is able to provide good detail on everything, including behavioral issues that he has faced. He said that his day was okay, but that his back hurt due to one of the Para's putting his knee in his back. I calmly asked why the Para put his knee in his back, and he rambled on about being put into isolation because he had become upset over an issue. I noted that there was some from of incident report in his folder, but there was nothing mentioned about him being restrained. I asked my son to show me exactly what happened. At this point, he showed me how to lie down on my stomach and put my hands behind my back. When I did so, he stood up, and put his knee into my back, and he held my hands with one of his tiny hands. I am almost 3x's my son's weight, and he hurt my back. The man that he told me did this is a heavy person, and so I wonder how that must have hurt my son. When I attempted to approach the teachers, I was met with denial, but I have to ask: How can an 8 year old come up with such a descriptive story?" My son has been put up on the wall as if he was a criminal and his hands put behind his back, and he has been held on the floor with his hands in front of him. What has this created for him: A feeling of helplessness, and low self worth?

Isolation in the classroom presents as a problematic issue in itself. My son is in a special education classroom for most of the day. He does get to go to a "regular classroom, but only for a certain amount of time each day or every other day depending on what the teachers feel he deserves. In the special education classroom, there is an "isolation room." This room is virtually a stone room, with carpet on the walls. My son has described numerous times about how he has had his fingers shut in the

HOUSE CHILDREN AND
FAMILIES
DATE: FEBRUARY 10, 2011
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door, how he has screamed to be let out, and how the teachers and or Para who has put him in has stood in the small window of the door and "taunted him," (he says) by turning on and off the lights in the room. My son often notes how he kicks that door and screams, which in my opinion shows an increase in the negative behavior. Just yesterday, my son had gotten into an argument with another student. My son described how he had tried to leave the room, and the Para's grabbed him. He then began to kick and scream, because he did not want to be touched. So he had to go to timeout. The first thing he asked me after he talked about this issue was; "Mom, why don't they like me?" This is followed by his own negative self talk about how he is an idiot, and how people just hate him. He does this every time he has been subjected to that room. So, at this point, I can only believe that isolation causes more negative behavior, but it also leads to low self esteem for the young ones that are subjected to it.

At this time, I wish to mention that I was given a job where I have worked with people with disabilities for a few years. Many of the clientele I have worked with had emotional and behavioral disabilities similar to that of my son's disability. I have gotten to speak with these people, and ask them how life was for them in school in an effort to better support my son, and many of them have disclosed similar stories to what my son is currently going through. Many have described similar types of rooms, and being restrained continually. The result is that these people grew up with the same low self esteem, feelings of worthlessness, and the same inability to interact in settings where there are people. This means that they cannot function in society!

Please do not take this letter to mean that children should get away with their behavior in schools, because I am not implying that. I feel that with all actions there are reactions. This means that for every behavior there is a consequence. No teacher or student should be hit, or made to feel unsafe in any environment that they are in. What I ask is that a program be created that allows a child to learn positively from their actions. At home when my son misbehaves, we do go to his room together, and I sit with him and discuss what has happened. If he is still angry, then I sit there and give him his space, but I let him know that I am right beside him to ensure that he understands that I am here for him, and I want him to understand why his behavior was unacceptable. My son taught me how to discipline him. If I show my frustrations while he is angry, he will feed off of me. If I make him feel powerless, he will fight harder for that power back. If I am calm and give him a consequence, though he does not like it, he does it. I know that school facilities do not have the man power to do this all of the time, but am sure that other options are available.

I have also noticed that when I have confronted the school system about the restraints, I am told that they have yearly one day training. This is another issue that I strongly believe warrants discussion. How can anyone learn all the restraints that have apparently is utilized in one day?

Please consider ever bit of information that I have provided you with. I am not only doing this as a mother concerned for her son, but as someone who has worked with individuals who were products of this form of discipline. The future results in some cases are not very positive.

Sincerely

A concerned parent

Keys for Networking, Inc.
Kansas Parent Information and Resource Center • www.keys.org
The State Organization of the Federation of Families for Children's Mental Health

February 10, 2011

Chairman Kiergerl and Members of the Committee:

Thank you for the opportunity to testify today. I am the director of Keys for Networking, Inc. We are one of the statewide nonprofits that assist families find services for Kansas children. Historically, we have specialized in securing mental health services. In the past two years, we have expanded our work to help families access medical cards whether through Medicaid or Healthwave. We then work with the family to learn the services available and how to access them. We work closely with schools to make sure children receive an education that prepares them for life.

As director of Keys for Networking I am a proponent of the enforceable standards in state law. I wish to give you examples of where the guidelines have been implemented and where they need to be. I believe the standards ensure fairness. The great schools do right things. Uninformed schools and uninformed parents don't know how and don't necessarily have the direction to do so. We need the standards because schools spend billions of dollars and there should be some standards and accountability in how schools use these dangerous and deadly tactics. Seclusion and restraint when practiced by untrained people is a deadly tactic. Seclusion and restraint mean in the worst sense "manhandling a child." There are ways to move and motivate children where only very trained staff move children against their will."

Our agency has witnessed remarkable changes in many districts/schools in the last three years. Most notably Atchison, USD 409 and Seaman, USD 345. Teams from these two districts have worked for months, years actually to work with students who were identified as "unteachable and unwelcome in the schools." For these children, mental health and school staff connect the resources of both agencies to support the child. Mental health staff work in the classroom along side the teacher, mental health experts provide training to the child's teachers specific to promoting peer relationships, learning social cues, managing impulsive behaviors and monitoring medication side effects. Teachers work closely with parents to practice the same discipline techniques and reward structures in both home and school.

Two mothers are here today. They may talk to you about how this integrated programming works. I believe it is important to think about what works and how well it works when schools, mental health providers and parents develop integrated plans of care. The outcomes for these youth are remarkable. This does not mean these children do not have problems. They have very serious emotional disabilities.

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As it happens both children were adopted. Janette and her husband, Jeff adopted one child, Jeremy and then learned that he had siblings. They adopted the other two children. Jeremy is a survivor of severe emotional and physical abuse and probably drug additions. His needs are so severe that he is served by the Mental Health Center through the HCBS waiver for youth with serious emotional disabilities (SED). His therapist, Mindy Kessler helped train his teachers to work with him. Jeremy and Jacob are the top most in need children in the state. I am asking Janette to speak when I finish to show you how this has worked. She has pictures and grade cards.

Jacob likewise is adopted. He has posttraumatic stress from seclusion imposed by the Atchison school district. His mother met him shortly after he was born in a Chicago hospital emergency room. His biological mother was a cocaine addict. Cherie, who is here today, has fostered 92 children. Like Janette, she will talk about the remarkable changes that a mental health team and a great school can make. In Jacob's case, Marillac, a psychiatric residential treatment facility worked with the Atchison school district to train teachers and Jacob to make this work. Cherie brings his grade card to show you that this young man is really ready to attend high school next fall. I spoke yesterday with Dr. David Meyers, Atchison special education director and he said planning is underway for this transition. He also said the district used the guidelines and expanded on them to make services work and to shape a healthy environment.

Compared to these stories, I have two that are very different. They sound though like the early stories of Jeremy and Jacob. One is about a high school student who fought her way out of a seclusion room in terror (this happened a year ago). She spent 30 days in a PRTF at a cost of $9,000 or $300 per day. This does not include the cost to her and her family. The other story is about a youth of 9 for whom the district has built his own room, which locks. From the outside. He cannot get out. He is alone. He spends his entire school day in this room every day. There are no logs to document. Educators work with him and hand him papers in the room. The police are called routinely as he throws fits, screams, and bites to escape the room. He has been hospitalized nine times in nine years. His IEP says he needs and responds to social interaction, wants to be with other children and needs physical activity to cope with anxiety. He too is served through the HCBS waiver for children with serious emotional disabilities. The district has filed with SRS, a child in need of care complaint because his mother cannot make him behave at school. I am not free to give this committee today more details about where these incidents occurred other than to tell you the high school incident occurred last year. The elementary school incident is going on now. I spoke with his mother and his therapist Tuesday night about 6 p.m. These stories are current.

My concern is this: some schools have responded to the guidelines and have absolutely used them to figure out good, safe non-seclusion techniques to work with little kids. The successes are remarkable and cost effective. Jacob and Jeremy are living with their families—with people who love them and want them. They go to their neighborhood schools. They have friends. Jeremy made a basket playing basketball with a little community team the other night. Janette said this was the single most important event in his life. He has a life. Jacob has a grade card that has all A's. He is ready for high school learning in a real curriculum, meeting state standards to move forward loves to read, has friends.

The two other youth, one a high school girl, one an elementary age boy are ostracized by the school, have no friends, are learning essentially nothing because no one works on anything but controlling them. Their districts have not responded to the guidelines and the stories are awful. I am surprised at how un-enlightened they are. With statues, I believe that all districts will recognize the need to work with youth, mental health providers and their families.

Thank you for listening to me. I wish for you to meet these hero mothers, Janette and Cherie. Janette's son is with her. They are coming from a doctor's appointment. I believe this is Jeremy's first visit to the Capitol.

Cherie Reynolds 1013 Parallel Street Atchison, Kansas 66002	Janette Keil 5347 NW Lincoln Topeka, Kansas 66618

INDEPENDENCE
INCLUSION
INNOVATION
INTERHAB

February 10, 2011

TO: House Committee on Children and Families

FR: Tom Laing, Executive Director, InterHab

RE: Seclusion and restraints and their applications and uses in school settings

We appreciate Representative Kiegerl's addition of this item to the committee's agenda this year.

We share the concerns expressed by many parents and advocates regarding the uses of seclusions and restraints on children with intellectual disabilities in school settings.

It is our hope that the committee will take seriously the recommendations in the testimony provided by Families Together and the Disability Rights Center and take steps to accelerate progress on a matter that has been debated and deferred too long.

Rather than attempting to shape the rights of children in ways that accommodate their academic setting, we should instead insist that education policies be shaped to accommodate the rights of children to be safe, and to be appropriately treated.

We believe that the majority of school settings are already moving toward best practices as regards the above referenced topic. We applaud administrators, classroom teachers and para-professionals who work to assure that each child is treated with the highest standards of care, compassion and with the most constructive responses to behavioral challenges which occur in the classroom and the school.

However, there apparently remain schools which need to be brought forward by the application and enforcement of required standards.

We urge the committee to take the constructive steps forward that have been suggested today.

Standards to protect children from inappropriate seclusions and restraints should not be mere suggestions, they should be required.

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