

In the Name of Treatment



**A Parent's Guide to Protecting Your Child
From the Use of Restraint, Aversive
Interventions, and Seclusion**



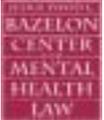
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VISION

All children with disabilities should grow up free from the use of restraint, seclusion, and aversive interventions to respond to or control their behavior, and from the fear that these forms of behavior management will be used on themselves, their siblings or their friends.

This publication was developed by APRAIS, with editorial assistance and funding support from the founding organizations. Photographs have been contributed by the families of children who have been harmed by the use of restraint, aversive interventions, and seclusion, and are used with their permission. This publication is dedicated to the memory of Matthew Goodman (1987-2002) and to all those children who continue to be abused and to die "in the name of treatment."

In the Name of Treatment: A Parent's Guide to Protecting Your Child from Restraint, Aversive Interventions, and Seclusion is available on the APRAIS web site, www.aprais.org. You may download a hard copy off the website. Print copies of this guide may be obtained from TASH by sending check or credit card authorization for \$5.00 per copy (includes postage) to: **TASH**, 29 W. Susquehanna Ave, Suite 210, Baltimore, MD 21204 (Please call TASH for information on bulk discounts).

For resources on Positive Behavior Support or more information about national efforts to promote safe, respectful, and effective behavior and education services and supports for children and youth with disabilities contact:

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The problem

Every day in this country, children with disabilities are needlessly being subjected to harmful practices in the name of treating "challenging behaviors." They are brought down to the ground and straddled, strapped or tied in chairs and beds, blindfolded, slapped and pinched, startled by cold water sprays in the face, deprived of food, secluded in locked rooms, and more, despite the fact that research and practice show that these techniques exacerbate challenging behavior and do nothing to teach the child appropriate behaviors. This guide, a joint effort of the founding organizations of APRAIS, is written in response to this alarming problem.



Matthew Goodman, age 14, died in February of 2002 after 16 months of physical and chemical restraint

Across the country, teachers, aides, and program staff who have been entrusted with children's care, protection, education, and development are subjecting them to this "treatment." In fact, such negative and dangerous activities are often inappropriately included as part of these children's education plans in the hope that they will reduce the occurrence of unwanted behavior. Children learn nothing about acceptable behavior from the experience of being hurt, secluded, or immobilized by their caregivers. Children with serious communication, social, and behavior challenges need effective, research-based, positive approaches based on Positive Behavior Supports (PBS). PBS teaches desired behaviors, useful skills, and fosters healthy emotional development and interactions with others. PBS is widely accepted as effective evidence-based practice that not only reduces even the most dangerous and disruptive behaviors, but focuses on the vision of quality of life.

Many parents are unaware that their children are being routinely hurt, restrained, secluded, and subjected to painful and ineffective practices by their school or program. Some have signed vague or confusing consent forms which offered no clear picture of the dangerous interventions planned for their child. Other parents are aware of and deeply troubled by the methods used on their child, but have been threatened with loss of the placement or other essential services if they object.

Every year, children with disabilities are injured, traumatized, and even die as a result of inappropriate and inhumane interventions.

The deliberate use of pain, humiliation, exclusion, and immobilization on a child has all the hallmarks of abuse. Most parents assume that a child with disabilities has the same protections against abuse that other children are given. Unfortunately, the programmatic application of these abusive procedures on children with disabilities is often treated differently. In many special education programs and service delivery systems the use of pain and humiliation (aversive interventions) and immobilization (restraint and seclusion) to control or change behavior is state-sanctioned - allowed under a confusing patchwork of outdated, poorly-written, or overly permissive laws and regulations. When abuse is permitted in this way, parents may find that the usual responses to child endangerment, such as seeking help from school administrators, the police, or the courts, fail to solve the

immediate threat their child is facing. When abuse is sanctioned, it becomes less visible. Injuries and deaths involving these procedures are believed to be significantly underreported. The kinds of investigations that would expose the nature and extent of the problem are seldom done, and accurate information based on medical or forensic reporting is difficult to obtain. The deaths and injuries of children with disabilities are too easily blamed on accidents or on aspects of the disability itself. But in recent years parents are speaking out, and advocacy organizations, legislators, and the courts are realizing the seriousness of this threat to the basic human rights of vulnerable children and youth.



Aversive interventions, restraint, and seclusion are used on children across the spectrum of disabilities, including those with autism, learning disabilities, mental health needs, cognitive challenges, and children with physical and sensory disabilities. Schools and programs continue to use aversive interventions, restraint, and seclusion for a variety of unacceptable reasons, for example: because they are understaffed; for staff convenience; because they think "bad behavior" should be punished; because they do not believe the children they serve have the same needs, rights, and feelings as children who do not have disability labels; or because the school or program lacks leadership and does not empower teachers and staff with the knowledge, support, and positive alternatives they need.

The use of aversives, restraint and seclusion has resulted in hundreds of deaths and thousands of injuries. Even when no physical harm is apparent, these techniques cause psychological trauma and rob people of their dignity.

The purpose of this publication is to help parents and families learn more about the dangers of the use of aversive interventions, restraint, and seclusion, and to assist them in keeping children safe while dealing in a positive way with challenging or inappropriate behaviors.

Definitions

AVERSIVE INTERVENTIONS

(or "aversives") involve the deliberate infliction of physical and/or emotional pain and suffering, for the purpose of changing or controlling a child's behavior. Aversives include (but are not limited to) techniques such as direct physical or corporal punishment (hitting or pinching); visual screening; forcing a child to inhale or ingest noxious substances; sensory deprivation; depriving a child of food, use of a toilet, or other health-sustaining necessities; and temporarily but significantly depriving a child of the ability to move. Use of restraint devices as well as blindfolds, visual screens, and white noise helmets results in sensory deprivation. Techniques that deliberately disrupt a child's basic emotional well-being and sense of safety, or that result in the long-term loss of the normal freedoms and pleasures of childhood by preventing exercise, peer interactions or other activities may also be considered aversive.

RESTRAINT is a type of aversive that involves the forced restriction or immobilization of the child's body or parts of the body, contingent on a designated behavior. There are three types of restraint. Manual restraint involves various "holds" for grabbing and immobilizing a child or bringing a child to the floor. The child is kept in the chosen restraint position by one or more staff person's arms, legs, or body weight. Mechanical restraint is the use of straps, cuffs, mat and blanket wraps, helmets, and other devices to prevent movement and/or sense perception, often by pinning the child's limbs to a splint, wall, bed, chair, or floor. Chemical restraint means using medication to stop behavior by dulling a child's ability to move and/or think. Medication specifically prescribed to treat symptoms of a disability or illness is not a chemical restraint.

It is generally accepted that brief physical intervention used to interrupt an immediate and serious danger to the child or others may be called for in the case of safety emergency. This is different from the ongoing use of restraint as punishment or in the guise of treatment for a child's disability or behavior. Frequent use of emergency restraint is an indication program revision is needed, even if the program is considered positive.

SECLUSION involves forced isolation in a room or space from which the child cannot escape. Allowing a child to voluntarily take a break from activities is not considered seclusion.

What are the dangers and risks to children?

Positive behavior interventions are safe in the short run, and in the long run promote habits and attitudes that continue to reduce risk. On the other hand, aversive interventions, restraint, and seclusion may cause injury and death, and they can backfire in ways that cannot be predicted or controlled. According to the professional literature, the following are some crucial considerations in choosing safe, respectful, and effective interventions:



- ♦ **Children generalize what they learn.** Anxiety and avoidance triggered by aversives, restraint, and seclusion will spread to other areas of a child's life and become an obstacle to achieving desirable behaviors, attitudes, and progress. For example, a child who experiences aversive procedures in the classroom will come to fear and avoid the classroom itself, the teacher, the school bus, the school, and the learning process in general.
- ♦ **Children learn from their experiences with adults.** Physically coercive activities teach children that "might makes right" and that physical means of problem-solving are acceptable. The small child who is easily restrained today will soon become a large, strong teenager able to demonstrate the dangerous behavior he/she has been taught.
- ♦ **We can help a child best by seeking the underlying cause of his or her behavior.** When aversive techniques, restraint, and seclusion are used to stop behavior for the short term, the real cause of that behavior goes undetected and unresolved. The underlying cause, whether medical, emotional, or social, is masked by these methods and can worsen as a result of the very techniques used.
- ♦ **Adults can teach children alternate ways to communicate.** Helping children learn new skills provides them with opportunities for achieving success. Aversive strategies, restraint, and seclusion do not offer the child useful alternative behaviors.

For instance, a child who is squirted in the face each time he or she screams is not learning new and better ways to communicate with teachers and staff or to solve the problem that is causing the screams.

- ♦ **Positive strategies can flourish only when negative interventions are rejected.** The use of restraint, seclusion, and restrictive techniques take time, training, and imaginative energy away from the search for positive strategies for children with disabilities. Teachers or staff may be caught in a cycle of negative responses from which it becomes increasingly difficult to escape.
- ♦ **Trusting relationships between a child and his or her teacher, combined with a sense of safety, are fundamental for healthy child development.** Aversives, restraint, and seclusion eliminate the opportunity for such an environment or relationship.
- ♦ **Children need to know that their bodies are their own, and that sometimes it is right to refuse or say "no."** When children are taught that it is appropriate for adults to grab and hold them, and that a "good" child should submit without objection, these children can become easy victims for sexual predators.
- ♦ **All children should enjoy equal protection from danger and risk.** Children with disabilities are already three times more likely to be abused than children without disabilities. Permitting dangerous activities labeled as treatment leaves this vulnerable group with unequal protection under the law.
- ♦ **When children with disabilities are taught alongside their typical peers, positive strategies are more likely to be the norm.** Schools and programs that use aversives, restraint, and seclusion tend to operate in segregated settings, away from public view, because these dangerous interventions violate community standards and values.

Considerations in choosing effective treatment



There are several important steps you can take to help ensure the safety of your child:

- *know your rights*
- *learn all you can about positive behavior supports*
- *evaluate your child's program*
- *be aware of the warning signs of abuse*
- *act promptly when you see a problem*
- *join with advocates nationwide to demand an end to the use of aversive procedures, inappropriate restraint, and seclusion*

The following pages provide in-depth information on each of these steps.

Trauma and Child Development



Practitioners of aversive techniques, restraint and seclusion used to believe that if the child was not physically injured by such interventions, they had done a safe job. Now we know better.

Advances in our understanding of child development emphasize the importance of a secure, well-balanced emotional life. A child repeatedly subjected to these techniques grows up feeling helpless, frightened, frustrated, or angry. The child's reactions may become increasingly stressed.

Over time, the overworked stress response system of the child's brain can become unbalanced, creating an ongoing state of high arousal. Repetitive, impulsive activity patterns, such as the "fight or flight" response, become locked in as the child's brain chemistry changes. The child becomes less able to control emotions, to pay attention, or to take in new information and use it to make appropriate decisions. Eventually, such a child may misinterpret even the well-intended actions of others as threatening.

These classic responses to trauma interrupt and can permanently alter brain development. They fuel a downward spiral in which teachers or program staff are both creating and responding to the child's anger and inflexibility.

Know your rights

There are no justifiable reasons for using aversive interventions, restraint, and seclusion. *Laws and regulations covering most children's service delivery systems generally agree that aversive interventions, restraint, and seclusion may not be used for purposes of staff convenience, or as coercion, punishment, or retaliation. These methods are not "teaching" methods because they do not teach positive behaviors. The use of aversive interventions, restraint and seclusion under the guise of therapeutic or educational interventions is unethical because these*

procedures create risk and unnecessarily take away basic rights. There is a lack of evidence that aversive techniques offer a safe means of teaching desirable, self-directed behavior that a child can maintain over the long term. Safe, positive methods of changing and redirecting behavior are well-documented.



Evidence shows them to be successful regardless of the child's diagnostic label, degree of disability, or severity of behaviors. The responsibility to employ best practices, and the obligation to do no harm in treatment require that the least dangerous, least intrusive, and least restrictive methods always be used.

Individual liberty is protected under the doctrine of least restrictive alternative (LRA). LRA requires careful consideration of the individual's interests; the purpose of treatment; and, the interventions and environments chosen to provide treatment. Additionally, interventions must be demonstrated as effective for the purpose for which they are used, and there must be proof of therapeutic justification. LRA, therefore, provides parents and advocates a strong constitutionally based argument in favor of positive interventions over the use of aversive interventions, restraint, and seclusion - all highly restrictive procedures.

The IDEA supports positive approaches for all students. *The Individuals with Disabilities Education Act (IDEA) creates a presumption in favor of positive methods, requiring an IEP team to consider using positive behavior interventions and strategies when addressing a child's behavioral concerns. A Functional Behavioral Assessment is the type of evaluation used to determine a child's behavior support needs. From this evaluation, a behavior*

What About Emergencies?

Aversive interventions and seclusion are not appropriate even in a safety emergency. However, brief physical intervention may occasionally be needed to prevent a child or those around him/her from immediate physical danger. Every parent respects the need to stop a child from darting into traffic or stop a child from a self injurious incident. It is also commonly understood that no child should endlessly repeat these experiences. Instead we must teach appropriate behavior and make indicated environmental changes. We must learn from emergencies so that they become extremely rare.

Some programs assure parents that they don't use restraint as treatment, yet their rate of emergency restraint is high. In these cases, it is likely that restraint "treatments" have simply been re-named restraint "emergencies." Observe what your child's program is calling an "emergency:" Is it a situation that staff escalated? Is it a situation that teachers or staff could have avoided by collaborating with you and your child to solve the problem at hand, or defused by using de-escalation techniques? Is risk to property used as an excuse for restraint? Are children being restrained when the risk of physical injury is relatively minor (e.g., a child is picking at his skin or banging on her desk)? Are children restrained on the grounds that their present activity might lead to danger at some future time? If any of these answers is yes, that situation is not a safety emergency, and restraint should not be employed.

intervention plan may be developed. Completing a Functional Behavioral Assessment means observing a child's behavior through a variety of methods and asking questions such as: What does the child achieve through the use of this inappropriate behavior? Why and when is it happening? How can we teach the child more desirable skills and behaviors that will allow him or her to achieve the same results in a more socially acceptable way? The concept of a Functional Behavioral Assessment has been highly developed in research and practice, and should lead to positive behavioral interventions and supports.

Emphasis on the development of new, positive skills is different from the use of aversive techniques, restraint or seclusion, which are applied solely to control or reduce unwanted behaviors.

Some states have clarified the language in IDEA even further, specifying in state law or regulations that all methods used to support children with disabilities in the schools must be positive. Check with your state Protection and Advocacy organization, Department of Education, or public interest education law office to learn what additional protections your state may offer.

The use of aversive techniques, restraint, and seclusion can lead to violations of the "free and appropriate public education" (FAPE) provision of IDEA. *Under IDEA, an appropriate special education program must be designed to provide the student with meaningful educational benefit. However, students do not learn meaningful lessons about alternative ways of communicating and interacting when teachers and program staff respond to their challenging behaviors with aversive interventions, restraint, or seclusion. Often the frustration and anxiety caused by these negative procedures cause the child's original behavior to worsen, or to be replaced by other equally undesirable activities. When children suffer a high degree of anxiety and stress, their ability to process, retain, and act on new information is severely compromised, further undermining their ability to access FAPE.*

The implementation of aversive techniques, restraint, and seclusion takes time and attention away from the child's IEP goals, so that educational progress is hampered. The use of these techniques, or even a request from the child's program for permission to use them, should immediately suggest that the student's programming is not effective. Parents can exercise their right to a new IEP meeting, at which all aspects of the student's IEP and behavior support plan should be reevaluated.

Does My Child Have Constitutional Protections?

The use of aversives, non-emergency restraint, and seclusion in facilities run by federal, state or local governments raises important issues of constitutional protections. Some courts have ruled against the use of these behavioral interventions on people with disabilities on the grounds that they violate the Eighth Amendment prohibition against "cruel and unusual punishment." Other legal decisions have found the Eighth Amendment to apply only to prisons and other penal facilities. This leads to a seemingly indefensible predicament: certain aversives and restraints permitted for "therapeutic" use on children with disabilities are considered too inhumane to be constitutionally applied as punishments in prisons.

Unjustified restraint use in public facilities has been successfully challenged as a violation of constitutionally protected liberty interests under the Fourteenth Amendment. The Supreme Court (in *Youngberg v. Romeo*, 1982) found that a man with mental retardation who was committed to a state facility had constitutional rights, including a right to reasonably safe conditions of confinement, freedom from unreasonable bodily restraints, and minimally adequate training. The Supreme Court thus adopted the position that persons involuntarily committed "retain liberty interests in freedom of movement and in personal security" and that providers risk liability when they use aversives or restraints.

The Children's Health Act of 2000 protects children in certain settings. *The Children's Health Act of 2000 sets a federal floor of protections covering children in "psychiatric residential treatment facilities" (PRTFs) under the Medicaid program, as well as those in "certain non-medical community-based facilities for children and youth." In these settings, restraint and seclusion may be used only to ensure the physical safety of the resident or others and may only be ordered by a physician or other professional licensed to order restraint and seclusion. Federal regulations from the Centers for Medicare and Medicaid Services (CMS) have further strengthened these protections for residents of PRTFs, requiring that a physician or licensed independent practitioner make a face-to-face physiological and psychological assessment of the*

child within one hour of the start of emergency restraint or seclusion. This statute and regulations represent a significant advance in no longer approving the use of restraint and seclusion as ongoing “interventions” for children. However, many residential facilities for children still are not covered by these rules.

Parents and others concerned about the inappropriate use of these interventions and other issues involving inadequate treatment or unsafe conditions in health care facilities may file a complaint with the regional CMS office or the facility's licensing agency in the state. CMS or the state will conduct an investigation and, if violations of Federal or State standards are found, will require the facility to implement corrective measures. Contact information for CMS regional offices may be found on CMS's website at <http://www.cms.hhs.gov/about/regions>; contact information for state licensing agencies may be found at <http://www.cms.hhs.gov/cli/ssa-map.asp>.

You have the right to be fully informed and to deny consent. Because of the dangers involved in using aversive techniques, restraint, and seclusion, programs wishing to use them must require children's parents or guardians to give “informed consent.” You have the right to refuse that consent. You may even wish to preemptively deny permission for your child's school or program to use these methods on him or her by using the model “No Consent Form” on page 15 of this publication. Remember that a special education program developed without parental input is in violation of the procedural requirements of IDEA.

Parents should beware of “stealth consent forms” that some programs try to slip under their radar when their child is admitted. These consent forms are vaguely worded, asking only for the parent or guardian's permission to use “restrictive procedures” (or some other unclear term). Parents may have no idea that “restrictive procedures” means more than latches on the windows or seat belts on the bus, but refers to aversive techniques, restraint, and seclusion.

Although called “informed consent,” the consent process seldom meets this standard because schools often fail to provide parents with all necessary information about physical and psychological risks to their child, and about positive alternatives. The request for consent may be questioned or challenged on this basis.

Parents have reported facing “coerced consent” when programs threaten to stop serving their child unless consent for aversives, restraint, or seclusion is given. It is important to seek a knowledgeable advocate or legal assistance if such threats are made. Your child maintains certain legal rights to continuity of placement and other services under the IEP, and often under other service contracts and regulations as well.

You have the right to fully informed and appropriately trained teachers and staff. These are some important questions to ask: Have staff been fully trained in positive means of support? Have they been trained in techniques of prevention, de-escalation, and redirection in the face of a challenging situation? Have they conducted a functional behavioral assessment? If restraint is being used, how were staff trained, are adequate numbers of trained staff always on duty, and is medical oversight adequate and readily available? Have staff tried all proposed interventions on themselves first? Do staff fully understand the laws, regulations, and ethics that govern their actions? Are staff fully aware of the physical and psychological risks to your child, and of the legal risks to themselves, if they resort to the use of aversive techniques, restraint, or seclusion? Programs and their staff face legal liability (and unwelcome publicity) when they make poor choices of interventions. Assuring that they are informed of these possible consequences often has a positive effect on staff behavior.

**Parental Discipline:
Not a problem
Aversive Programs:
Not a solution**

Protecting children from the programmatic use of aversive techniques, restraint, and seclusion has no effect on parents' right to discipline their offspring, to say “no,” or to respond to emergencies. To reject these methods is to limit professionals' rights to design and implement an ongoing program based on pain, humiliation, or immobilization.

Such a program cannot be equated with everyday family discipline, such as saying “no” to a child's unreasonable request. It also cannot be equated with one-time reactions to behavior in the face of emergencies (e.g. grabbing a child to get him/her out of the path of a vehicle), since that is not a behavior program.

Learn about Positive Behavior Support

Behavior that challenges us is a symptom of a problem, not the problem itself. It tells us to look closer and listen harder, because something is wrong. Behavior problems are messages about what is happening in someone's life. By joining in the communication, rather than shutting it down, we can identify the problem and find positive solutions.

More than two decades of peer-reviewed studies have provided strong evidence of positive alternatives for addressing even the most serious behavior challenges, such as self-injury, aggression, and property damage.

The success of Positive Behavior Support (PBS) has been documented across settings, including schools, family homes, and typical places in the community. Because PBS is not intrusive or inappropriate for public places, PBS supports and encourages children to participate more fully in normal everyday activities and community life.

PBS, which is based upon a completed Functional Behavioral Assessment, is an evidence-based technology and process for developing effective, individualized, nonaversive interventions for children whose behavior challenges us. PBS draws information from psychology, medical research, and neuroscience to understand how learning and long-term behavior change occur.

The goal of PBS is not merely to suppress or eliminate unwanted responses but to understand and respond thoughtfully to its cause and/or purpose. The child can then be assisted to substitute more appropriate and effective behaviors, including better ways to make his or her feelings, needs, and choices known.

The Positive Behavior Support approach also involves evaluating a child's physical environment and changing those things or events that are overwhelming or stressful (e.g., loud noises, crowded situations, unstructured time, inappropriate instructional strategies, lack of adaptations in curriculum). Last but not least, it involves a commitment to changing attitudes and behaviors on the part of adults with whom the child interacts.

Key Elements of Positive Behavior Support (PBS)

PBS is an orientation based on research, one that aims to build a culture of support by understanding the function of behavior; creating individualized and socially meaningful supports; creating person-centered environments; and using a collaborative team approach.

To accomplish this PBS focuses on:

- Understanding through Functional Behavioral Assessment and hypothesis-based interventions that are selectively determined based on an individual's needs, characteristics, and preferences;
- Prevention and early intervention;
- Education and capacity building;
- Utilization of long-term, comprehensive approaches;
- Involvement and ownership of key stakeholders; and,
- Commitment to outcomes that are meaningful for that individual.¹

Focusing solely on the reduction of problem behaviors through the use of positive or negative consequences, and/or simply reinforcing appropriate behaviors by itself is not PBS.

Positive Behavior Intervention and Support involves teaching new skills that replace challenging behavior over time, assisting the individual to change his or her interactions (physical and social), teaching staff to change their behavior, and must be based on the conduct of a Functional Behavioral Assessment.

Further resources on PBS can be found on the APRAIS website www.aprais.org and other sites listed on page 18 of this guide.

¹ Carr, E.G., Dunlap, G., Horner, R.H., Koegel, R.L., Turnbull, A.P., Sailor, W., Anderson, J.L., Albin, R.W., Koegel, L.K., & Fox, L. (2002) Positive Behavior Support: Evolution of an Applied Science. *Journal of Positive Behavior Interventions*, 4, 4-16, 20.

Evaluate your child's program

There are important differences between schools and programs that employ aversive techniques, restraint, and seclusion, and those that have made a full commitment to positive approaches. To evaluate whether a program can deliver on its promise of positive approaches for all, parents should observe the following:

- ◆ **Is there clear evidence of positive, involved, and supportive leadership?**

A safe, positive school or other program requires leadership from the top, as well as determination that all administrators, teachers and staff adopt a shared vision of how children should be nurtured and respected. This creates a culture of shared goals and shared communication, encouraging teachers and staff to support each other and communicate with parents and children to solve difficult problems.

- ◆ **Do teachers and staff plan ahead rather than just react?**

Implementing aversive techniques, restraint, and seclusion wastes the time and energy of teachers and staff, keeping them trapped in a stressful, reactive posture. The use of negative interventions on one child also raises the fear and anxiety levels of other children, setting the stage for further problems to emerge and spread throughout the program. Quality service provision requires teachers and staff to be organized and proactive. Positive programs keep staff focused on ways to anticipate and prevent problems rather than merely responding to the challenging behavior after it has occurred.

- ◆ **Do children receive the positive attention, quality time, and meaningful activities they need to thrive?**

Negative interventions are by nature isolating and disruptive of human relationships. They may result in external compliance at the expense of internal motivation, a condition known as "learned helplessness." Restraint and other negative interventions are also labor intensive, taking multiple staff members away from other children and leading to their neglect. In positive settings the time and attention of teachers and staff can be more equitably shared and trusting relationships can

be built. This increases the program's ability to implement positive behavior support program-wide. Children become self-motivating as they experience activities that are socially desirable and academically meaningful.

- ◆ **Do teachers and staff listen to and respect the children and families they serve?**

The acceptance and use of aversive techniques, restraint, and seclusion reduces the quality of services through "program drift." This is the process by which a service culture founded on care and support can deteriorate over time into a culture of devaluation and coercion. Positive programs eagerly seek parents' expertise about their child, not parents' consent to use dehumanizing interventions on their child.

- ◆ **Is the program able to attract and keep good, dedicated teachers and staff?**

Using aversive interventions, restraint, and seclusion as part of children's education or treatment plans can reduce the quality of staff and lower job retention. Staff are denied the satisfaction of developing trusting, cooperative relationships with the children they support, find themselves locked into increasingly stressful encounters with fearful and angry children, and are at far higher risk of personal injury.

Should Quick Fixes Ever Be "A Part of This Healthy Plan?"

You've seen it in the ads from the breakfast cereal industry: a place setting with eggs, toast, milk, fruit.....and right in the middle a big bowl of Choco-Crunchies, carefully labeled "a part of this healthy breakfast."

Well, it may be a *part*, now that the photographer placed it there, but it's certainly not a healthy part! The same advertising logic is employed by schools and other programs that try to insert aversives, restraint, and seclusion into a child's "positive behavior support plan."

Like the child drawn to that sugar high, program staff are attracted to their own quick fix and never get around to checking out all the healthy, positive offerings that can be found on the table.

When coercive interventions are permitted they become the "junk food" of education.

Be aware of the warning signs of abuse

A particular child may be too young to give parents information directly, may not speak due to his/her disability, or may be embarrassed or afraid to "tell on" adults in authority. Many children assume that their parents must already know and approve of what is being done to them. Therefore a lack of specific complaints and information from children does not guarantee that aversives, restraint, or seclusion are not being used on them in their school or program. Parents need to be vigilant detectives.

The Myth of Safe Restraint

For many years, service providers and staff trainers have searched for a perfect, safe method of restraint. We now know that no such thing exists. Not only are psychological risks present with each restraint use, but physical risks now appear to be inevitable.

Children with disabilities can be medically complex. Many are chronically ill and may suffer from pre-existing conditions such as sleep apnea or difficulties in the regulation of body temperature. The prevalence of gastrointestinal problems makes many children especially susceptible to aspiration (choking on food or vomit) under stress. Another risk is thrombosis (clots in veins) which can form during prolonged restraint in one position. Many children are being medicated with pharmacological agents that may be cardiotoxic, precipitate arrhythmia, or trigger respiratory problems or electrolyte imbalances, particularly when they interact with the intense agitated states and surges of adrenaline that occur during restraint.

Then there is the human factor. When staff pit their body weight against a child's smaller frame, especially when the child may be agitated and in distress, the result can never be certain. Terrified children fight back, and restraint situations can escalate rapidly and unpredictably. Staff may continue a restraint until the child stops struggling, not realizing that the child is actually struggling to breathe. There have been many cases in which children have died due to restraint for a minor incident that escalated out of control.

For many parents, the first clues they see are unusual injuries.

Sometimes a parent will find bruising or abraded, reddened skin on arms, wrists, or ankles. There may be marks from fingernails, rug burns, or unexplained patterns of abrasions

and bruises, sometimes hidden under the child's clothing, which are unlike the scraped knees and elbows children acquire during play.



Other useful clues can be found in the "incident reports" that programs are supposed to send home following a problematic episode. If a daily journal or diary is sent between school and home, parents should note and question too many entries with remarks such as "a rough day."

Sudden regressions in behavior or the emergence of new and unexplained behavior problems may indicate psychological distress and offer clues to their origin. Newly-emerging behavior may include: sleeplessness, increased anxiety levels; emergence of a school phobia (especially when the child previously enjoyed attending school) or of a more generalized fear of leaving home; emergence of specific fears that may be related to particular aversive, restraint, or seclusion techniques (such as fear of spray bottles, seatbelts, or closets); appearance or intensification of self-injurious behaviors; a sudden change in weight; decrease in sociability; and increased aggression or emotional outbursts.

Note: The warning signs of abuse may be attributable to other hidden causes, such as sexual abuse. Such activity can be particularly difficult to discover, but unlike aversives, restraint and seclusion these types of abuses are illegal in all states.

As with any sudden change in a child's everyday habits and ability to cope, it is important to see a doctor or other professional to rule out other possible causes.

Act promptly to stop abuse

It is important that you make it clear to your child's teachers or other program staff that you expect an environment free of aversives, non-emergency restraint, and seclusion. You should also expect the elimination of emergencies to be a priority. To put this message on record, sign and date the "No Consent Form" in this publication and have it placed prominently in your child's IEP or treatment plan.

If you have seen warning signs which you believe may result from the way your child is treated at school, or in any situation where you are not present, it is important to ask questions immediately.

Review your child's records (especially the contents of the education and/or treatment plan, and any "incident reports" in your child's files), and make visits during which you carefully observe all aspects of your child's day.

Keep careful records. Document and date anything your child says or does that concerns you; take and date photographs of any suspicious injuries.

Share your concerns with your child's physician, psychologist, or other health care provider.

There are a number of ways to report abusive practices and seek help:

- ◆ If you have witnessed, or have evidence of abuse of a child, you have the right to call the police. The rule of thumb is: if you would call for police intervention to stop this from happening to a child without disabilities, you should call to stop it from happening to a child with disabilities.
- ◆ Your State Education Agency (SEA) will have a help line, hot line, or other assistance program to which you should report at once.
- ◆ Disputes involving your child's rights under the Individuals with Disabilities Education Act (IDEA), state special education regulations, or state school disciplinary laws and regulations can be addressed through an impartial due process hearing. You have the right to request a hearing concerning your child's placement or program at any time, and your request must be granted promptly. Your request requires a statement of the problem, and a proposed

The Protection and Advocacy System

The Protection and Advocacy (P&A) System is a nationwide network of congressionally mandated disability rights agencies. It has long been involved in redressing improper aversive practices, restraint, and seclusion. These agencies, which can be found in each state, provide helpful information to parents and consumers on these issues, as well as direct legal representation and referrals to other advocates.

A primary mandate of each state's P&A office is to investigate abuse and neglect of persons with disabilities in all settings and to pursue administrative, legal, and other appropriate remedies to ensure the protection of their rights.

More information on the P&A System, along with contact information for all P&A's nationwide, may be found at www.ndrn.org.

solution. A parent who wishes to file a request for due process should make sure they have included all required information and may need to consult an attorney or experienced advocate for advice on how to proceed.

◆ *The Office for Civil Rights (OCR) in the U.S. Department of Education provides the primary administrative enforcement for Section 504 of the Rehabilitation Act and for the Americans with Disabilities Act (ADA), two civil rights statutes that address discrimination, equal access, and reasonable accommodations, as these laws apply to schools. Section 504 prohibits discrimination against persons with disabilities on the basis of their disability. To demonstrate violation of Section 504, parents would need to show that aversive techniques, restraint, or seclusion were used on students with disabilities who engaged in certain behaviors, but were not used on students without disabilities when they engaged in similar behaviors. The ADA addresses the need for accommodations and access in public places and might be involved,*

for example, if a student is restrained or secluded "for his or her own safety" when environmental modifications would have made this unnecessary. Complaints about the use of restrictive and unsafe practices, and lack of the accommodations that would make these practices unnecessary, can be lodged with OCR for investigation. If necessary, all OCR and SEA hearing reports may also be appealed to federal court.

- ◆ *Complaints under the Civil Rights of Institutionalized Persons Act (CRIPA) can be made to the Civil Rights Division of the U.S. Department of Justice (DOJ). CRIPA gives the DOJ authority to bring legal action against state and local governments for permitting dangerous conditions and unsafe practices that violate the civil rights of persons placed in publicly operated facilities, including schools.*

- ◆ *States also may have public interest education law projects and disability law projects that can provide you with important information and may be able to provide direct advocacy.*

- ◆ *Some states have established an Office of the Child Advocate to investigate allegations of systemic abuse and neglect of children within that state's service systems. This can be an important contact, especially when a group of parents comes forward with similar complaints.*

- ◆ *All 50 states, The District of Columbia, Puerto Rico, and the federal territories have a protection and advocacy system (P&As). P&As are mandated under various federal statutes to provide protection and advocacy on behalf of individuals with disabilities. To find your state P&A contact information go to the National Association of Protection and Advocacy Systems website www.ndrn.org or call 202-408-9514.*



Until all children with disabilities are equally protected under the law from abusive practices — regardless of their disability, where they live, or which funding stream serves them — parents will need to employ a combination of these approaches to ensure their child's safety.

The Segregation Connection

What would you do if you witnessed a child being slapped by adults or found that your neighbor's child was locked in a closet? You most likely would be outraged and seek help. Teachers and other service providers would face the same public outrage if their use of aversive interventions, restraint, and seclusion were on public display. Because the classrooms and programs that use these procedures are overwhelmingly segregated and easily hidden from public view, most people do not know that these things go on.



States and service systems that have the most tolerance for aversive techniques, restraint, and seclusion tend to have the least inclusive schools and the fewest community living opportunities. The more these coercive techniques are used, the easier it is for professionals to convince themselves and others that segregation is inevitable.

Many advocates believe that the problem of aversives, restraint, and seclusion is closely connected to the problem of segregation. They believe that the safety of people with disabilities depends on their ability to enjoy visible and valued lives in their neighborhood schools and home communities. As families work to keep their children safe, it is important to remember that safety depends not only on statutes and regulations. It depends on inclusion in a wide network of caring relationships.

No Consent Form

This is a sample letter for parents to give to their school to deny permission to use aversive procedures. It is adapted by TASH from a letter written by Tricia and Calvin Luker of The RespectABILITY Law Center. Please feel free to change and personalize to best fit your specific needs. This letter is available electronically at www.aprais.org

(School District)
(Address)

(Your address)
(Your telephone number)
(Date)

Re: child's name and birthdate

Dear (Principal, Program Director, or IEP Team Leader):

My child, **child's name**, is a _____ grade student at _____ school. **Child's name** has a disability (or insert label) and is receiving special education services. I want to thank you for all of the help and positive support you and the teachers and staff at **name of school** have provided **child's name** over the years.

We are concerned that **child's name's** behavior challenges are being, or might in the future be, addressed in part through the use of aversive interventions, restraint or seclusion (including seclusionary time-out or procedures referred to as "physical management" or "restrictive procedures"). Examples of these practices include, but are not limited to: forcible holding or dragging, the use of ties or straps, sprays in the face, slaps, deliberate humiliation, deprivation of nutrition or exercise, and time out rooms. This letter is to make clear that I have not authorized and will not consent to any activity that involves the use of any of these procedures at school or while **child's name's** is transported to or from school. I know that The Individuals with Disabilities Education Act (IDEA) creates a presumption in favor of positive methods, requiring an IEP team to consider using positive behavior interventions and strategies when addressing a child's behavioral concerns. If the school feels **child's name's** behavior is so challenging that aversive or restrictive procedures, seclusion, time out, physical management, or restraint are being considered or used, it is clear to me that there is need for a FBA and the development of an effective PBS plan. I expect to participate in this assessment and the development of a PBS plan for my child.

I am sure you are aware of the number of news reports in recent years describing the deaths, trauma, and injury of children with disabilities while or just after being subjected to aversive interventions, restraint, or seclusion. I am writing this letter as a precautionary action and to provide clear instructions that none of these techniques are to be used with my child. If any of these techniques are currently being used, or have in the past been used, it is important that you notify me of this and terminate any use of such procedures immediately.

If **child's name's** behavioral issues are a challenge now or at any time in the future, I am requesting that a behavior support team meeting be convened to discuss these challenges, plan for an FBA across environments, and begin work toward establishing a positive behavior program to address **child's name's** particular needs. I wish to exercise my right to participate in all such meetings.

I want to work with you and with **child's name's** teachers and professionals at **name of school** to be sure that **child's name** learns to develop positive behavioral skills in an environment that is safe for **him/her**, for **his/her** peers, and for school personnel. I, like you, want my child's school to be a safe and secure environment where all students can learn. I want to work with you to help create that environment.

Sincerely,
(Your name)

Join with other advocates

JOIN WITH OTHER ADVOCATES NATIONWIDE TO END ABUSIVE INTERVENTIONS

According to the National Association of Protection and Advocacy Systems (NAPAS) 2004 Annual Report, the misuse of restraint and seclusion has resulted in hundreds of deaths and thousands of injuries in recent years. Children with psychiatric, cognitive, or other disabilities are especially vulnerable. These abusive interventions can re-traumatize people who have a history of abuse or assault, and rob individuals of their dignity.

The President's New Freedom Commission on Mental Health (July, 2003) found that high restraint rates should be considered as "evidence of treatment failure." The Commission noted that while many facilities and state agencies have had substantial success in reducing the use of restraint, "much work remains before this cultural change can occur." The Commission recommends that states develop mechanisms to report deaths and serious injuries resulting from the use of restraint and seclusion, ensure that investigations of these incidents occur, and track patterns of restraint use.

The Alliance to Prevent Restraint, Aversive Interventions, and Seclusion (APRAIS) has been founded by major national and state disability organizations to address prevention from several directions. We are working at the national level to assure children with disabilities of equal protection across funding streams and service delivery settings, and of adequately staffed and funded systems of reporting and accountability to back up these protections. We are working to convince the states to raise the bar on child safety. And we are partnering with individual parents and advocates, encouraging them to support and inform each other and to act as local watchdogs.

Keep APRAIS informed, through the web site www.aprais.org, of what is happening in your state or to your family, or to submit a picture or story. In turn, we will keep you informed of upcoming opportunities to bring about long-overdue changes in the laws and regulations that should protect our children.

Inequality in Child Protection

A commitment to the safety of children means that ALL children must be protected from dangerous and demeaning interventions. Yet we still live in an environment that tolerates unequal protection. Across the states, across service delivery systems, and across disability labels, child protections vary widely for no logical reason.

A child with disabilities may lose vital protections simply by moving out of the foster care system and into a residential facility, or may gain regulatory protections in the classroom when his family moves to another state. Families are often unaware of the losses or gains in rights that may occur when their child moves to a different state or service system.

Children without disabilities generally enjoy far greater protection than their siblings and peers with disabilities. Even among children diagnosed with disabilities, some are safer than others. Children with severe disabilities, who are presumably the most vulnerable, are also the most likely to be subjected to the most stressful, frightening, and dangerous interventions.

www.aprais.org

How big is this problem?

There are no uniform requirements for schools, public or private agencies, or residential facilities to report injuries or deaths of the children or youth they serve. This makes determining the size and scope of the problem quite difficult. A preliminary effort to gather data was made by Eric M. Weiss and the investigative reporters of the Hartford Courant as part of their ground-breaking series "Deadly Restraint," published beginning October 11, 1998. The data in that article indicate that 142 restraint deaths were recorded across the country between 1988 and 1998. Adolescent youth were disproportionately represented in this data. In addition, The Courant commissioned a statistical estimate from the Harvard Center for Risk Analysis which estimated that between 50 and 150 deaths from the use of restraint occur each year - that is 1 to 3 deaths per week.

Take time to inform and educate state and local policy makers about your experiences and concerns regarding the need to eliminate the use of restraint, seclusion, and aversive procedures from your child's school or support programs. Advocate for high quality educational services and programs that practice positive approaches and respectful, person and family-centered problem solving to address challenging behaviors.

The children pictured here are just a few of the too many individuals who were hurt or who died "in the name of treatment." This guide is dedicated to them and to their families, and all other victims of abuse who are unknown and whose stories are unreported.

Matthew Goodman



Matthew, who was labeled with autism, is remembered by family and former teachers as an active, curious, sociable, and funny child. At age 13 Matthew's residential school placed him in splint-like arm restraints (citing concerns that he was picking at his skin), later adding a large hockey mask. Against the protests of his parents, he was made to wear these restraints during the day and at

times during the night. In addition to mechanical restraint, Matthew was frequently chemically restrained with medication. He spent many days lying listlessly on the floor, until one day staff could not obtain vital signs. In 2002, Matthew died of pneumonia and sepsis after 16 months of restraint.

Jessica Baccus



Jessica, was victimized by seclusion and restraint as an eight-year-old. Jessica had epilepsy and cognitive disabilities. The school forced her to wear a seat belt during class, causing her a greater injury during a seizure. The school also placed her in a time-out/seclusion room a number of times. When Jessica banged on the door to be released school personnel taped her hands behind her back and when she screamed they slapped her.

Jason Tallman



Jason was a very bright, active boy who had read every Tom Clancy book and most of Michael Crichton's. He would act out and cause distractions in school, possibly due to boredom. Because of his behavior he was home schooled, then placed against his parents wishes in a residential facility on May 11, 1993. On May 12th he was restrained, causing him to pass out. Jason died on May 13, 1993. He was 12 years old.

Logan Gentry

Logan, who was labeled with autism, went through an extended period of time where he was educated alone in the bowels of a high school football stadium. Physical restraint was used against him whenever he resisted staff direction.



Calvin Wade

Calvin, who was labeled with Prader Willi Syndrome and associated cognitive disabilities, died while being restrained at school in December 2003, just days short of his 13th birthday.



Resources

References:

Achieving the Promise: Transforming Mental Health Care in America. Final Report, July 2003.

Available online: <http://www.mentalhealthcommission.gov/reports/FinalReport/downloads/FinalReport.pdf>

Bambara, L.M., Dunlap, G., & Schwartz, I.S. (2004). *Positive Behavior Support: Critical Articles on Improving Practice for Individuals with Severe Disabilities*. PRO-Ed, Inc and TASH.

Available to order online at www.tash.org

Bazelon Center for Mental Health Law (2003). *Suspending Disbelief: Moving beyond punishment to promote effective interventions for children with mental or emotional disorders*. Washington, D.C. Available online: www.bazelon.org/issues/children/publications/suspending/suspendingdisbelief.pdf

Kennedy, S.S. & Mohr, W.K. (2001). A prolegomena on restraint of children: Implicating constitutional rights. *American Journal of Orthopsychiatry*, 71(1), 26-37.

Available online: www.sheilakennedy.net/everything/ChildrensRights.html

Mohr, W.K., Petti, T.A. & Mohr, B.D. (2003). Adverse effects associated with physical restraint. *The Canadian Journal of Psychiatry*, 48, 330-337.

Available online: www.cpa-apc.org/Publications/Archives/CJP/2003/june/mohr.pdf

National Technical Assistance Center for State Mental Health Planning (2002). *Eliminating the Use of Seclusion and Restraint: Special Edition of NTAC Networks*. Alexandria, VA.

Available online: www.nasmhpd.org/general_files/publications/ntac_pubs/networks/SummerFall2002.pdf

Perry, B.D., Pollard, R.A., Blakley, T.L., Baker, W.L., & Vigilante, D. (1995). Childhood Trauma, The Neurobiology of Adaptation and Use-Dependent Development of the Brain: How States Become Traits. *Infant Mental Health Journal*, 16, 271-289.

Available online: www.trauma-pages.com/perry96.htm

Turnbull, H.R., Wilcox, B.L., Stowe, M., Raper, C., & Hedges, L.P. (2000). Public Policy Foundations for Positive Behavioral Interventions, Strategies, and Supports. *Journal of Positive Behavioral Interventions*, 2, (4), 218-230. Available online: <http://www.beachcenter.org>

Turnbull, H.R., Wilson, B.L., Turnbull, A.P., Sailor, W., & Wickham, D. (2001). The IDEA, positive behavioral supports, and school safety. *Journal of Law and Education*, 30(3).

Available online: http://www.findarticles.com/p/articles/mi_qa3994/is_200107/ai_n8985622

U.S. General Accounting Office (1999). *Improper Restraint or Seclusion Places People At Risk*. (GAO publication HEH-99-176). Washington, D.C.: USGAO.

Available online: www.gao.gov/archive/1999/he99176.pdf

Weiss, E.M. (1998). *Deadly Restraint: a nationwide pattern of death*. *Hartford Courant*, October 11-15. Available online: www.copaa.net/newstand/day1.html

Web sites offering further information on Positive Behavior Support:

www.pbis.org – This web site of a Technical Assistance Center on Positive Behavior Interventions and Supports is funded by the U.S. Department of Education.

www.rrtcpbs.org - The Rehabilitation Research and Training Center on Positive Behavior Support, headquartered at the University of South Florida, is also funded by the U.S. Department of Education.

www.apbs.org – The Association for Positive Behavior Support is an international membership organization dedicated to expanding knowledge and dissemination in the field.

www.beachcenter.org – The Beach Center on Disability provides family-friendly, research-based information on positive approaches and school issues.

www.icdl.com - The Interdisciplinary Council on Developmental and Learning Disorders (ICDL) offers research and training in positive approaches to supporting the development of children's capacities to relate, communicate, and problem-solve.

www.tash.org - TASH is a membership association focused on the elimination of barriers to full inclusion. TASH has extensive research and information relating to positive behavior support.