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Eight Frequently Asked Questions about Matthew's Law

1. *What new protections or advantages would Matthew's Law offer to vulnerable children and adults with disabilities in New Jersey facilities?*

Matthew's Law would require simple but vital protections that are NOT currently mandated in New Jersey when restraint is used as part of a person's "habilitation plan"—

- Limit restraints to serious emergencies only and prohibit aversives ("punishers" such as forcing the person to inhale noxious substances, water squirts in the face, slapping and hair-pulling), which have no emergency use
- Require medical oversight as soon as restraint begins, and a medical examination when it ends
- Require that parents or guardians be notified right away of any restraint use
- Require that a full team meeting, including parents and guardians, be held after any restraint use so that better plans can be made to prevent a recurrence
- Require that any and all restraints be reported to the Division of Developmental Disabilities, which must then issue this information to the public on a quarterly basis, facility by facility
- Require that facility staff be trained in a variety of positive approaches, communication strategies, relationship-building, environmental supports and accommodations, and other safe techniques

All of these protections are based on common sense, safety, and the right to full disclosure of needed information.

2. *Are these protections in place anywhere else?*

YES! The Centers for Medicaid and Medicare Services (CMS) prohibits non-emergency restraint use in facilities receiving federal funding, as does the Children's Health Act of 2000. Most states have prohibited non-emergency restraints and other aversives for years. The norm is: if it cannot be done to non-disabled children or adults then it cannot be done to vulnerable individuals with disabilities. Imagine the outcry if a teacher tied a non-disabled student down or methodically squirted him in the face to "change his behavior"; consider how quickly the police would be called and the county youth protection agency would intervene if a parent pulled her child onto the ground in a basket hold in the middle of the mall, or forced her to wear immobilizing arm restraints at the

Matthew's Law would result in

- Higher safety standards
- More accurate reporting
- Better staff training

People with developmental disabilities have the right to equal protection under the law

playground. Children and adults with disabilities deserve the same compassion and protection.

3. *Would Matthew's Law prohibit ALL use of restraints?*

NO! Restraints may sometimes be needed in emergency situations to prevent serious injury to an individual or those around him or her. However, restraints are always potentially injurious or lethal and must be employed sparingly and with great respect. ALL of the mainstream disabilities advocacy organizations agree that "Restraints are not treatment; restraints are the failure of treatment."

Matthew's Law does NOT prohibit all restraints

While some facilities and programs may continue to define "emergency" more liberally than others, this situation will gradually self-correct because the other requirements of Matthew's Law – physician oversight, parental notification, post-restraint planning meetings, and strict reporting requirements – will make it less practical to fall back on restraint as a quick fix. Overall restraint use will then decline over time. While rates decline, medical oversight will be in place to spare clients from injury or death.

4. *Do physicians really need to be involved when restraint is used?*

YES! Average facility staff persons (many of them with high school educations or G.E.D.s) and even LPN and associate degree (two year) registered nurses should not be making independent assessments in critical situations. In fact, it is unfair to them to place them in a situation of liability where they are outside the range of their knowledge and ability.

People with developmental disabilities are often medically complex

People with developmental disabilities and traumatic brain injury are not just cognitively challenged but medically complex. Many tend to be chronically ill and may suffer from known or unknown pre-existing conditions such as sleep apnea and difficulties in the regulation of body temperature. The prevalence of gastrointestinal problems makes many individuals especially susceptible to aspiration (choking on food or vomit). Another common risk is thrombosis – clots in veins – that can happen when a person is left in one position too long. Many, if not most, individuals in public and private facilities are being medicated by pharmacological agents that may be cardiotoxic, precipitate arrhythmias, or trigger respiratory problems and electrolyte imbalances, particularly when they interact with the intense agitated states and surges of

adrenalin that occur during restraint. Evaluating the interactions and side effects of our vast and changing array of medications is a job requiring years of specialized medical training and experience.

Restraints are very serious and can have serious consequences: injury, trauma, or death. It is both prudent and humane that every safeguard be in place if they are to be used on vulnerable, medically complex individuals.

5. *Wouldn't more and better staff training in how to apply restraints solve the safety problem?*

NO! While state-of-the-art staff training is always necessary, it is NEVER SUFFICIENT TO ASSURE CLIENT SAFETY. All current training materials on restraint fail to communicate the serious nature of its use, and the fact that it can and does result in injury, death, or trauma. No level of staff training can impart sufficient knowledge of the many complex physical and pharmacological issues an individual client may present. No advance in staff training can make non-medical personnel adequate to the task of providing medical assessment and monitoring. Only physicians have the necessary training in assessment of symptoms and behaviors, physical examination, and the formulation of diagnoses and treatment strategies.

Non-medical, direct care staff cannot provide medical assessments

6. *Is it ever appropriate to use restraints or aversives as a fast way to stop a behavior?*

NO! It is well documented in the literature of behavior change for persons with disabilities that non-emergency use of restraints and other aversives backfires for the following reasons—

- Their effects generalize to unwanted domains (e.g. a child restrained in the classroom may come to fear and avoid not only the so-called “target behavior” but the classroom itself, the teacher, the school, and the learning process in general).
- Restraints and aversives teach that might makes right, and that physical means of problem-solving are acceptable.
- Restraints and aversives are incapable of teaching useful alternative behaviors. For instance, if a child is squirted in the face each time he screams, the child is not learning new and better ways to communicate with staff or to solve the problem that is causing the screams.
- Restraints and aversives increase the anxiety levels of vulnerable people. Increased anxiety prevents the learning of

Restraints and aversives do not produce long-term improvements

new information and skills, and often increases ritualistic, repetitive, and even self-injurious behavior.

- Restraints and aversives take time, training and imaginative energy away from the search for alternative strategies for the individual with disabilities and staff.
- Restraints and aversives destroy the trusting relationship between an individual and his/her teachers or aides that is essential to learning and progress
- Restraints and aversives involve staff persons in coercive, “us vs. them” interactions and value judgments, which prevent them from empathizing with and gaining insight from the client. Staff members become involved in power struggles that escalate over time because they can see no alternatives. When non-emergency restraints and other aversives are removed from a program, everyone is empowered to find more functional and humane ways to support and accommodate vulnerable people with disabilities.

7. *Each time these techniques are used, clients are at risk for injury, severe psychological trauma, and even death. Are there proven, effective alternatives to restraint and aversives, and is this information easily accessible?*

YES and YES! Starting nearly two decades ago, the National Institute on Disability and Rehabilitation Research launched an intensive nationwide program of research grants, testing, and evaluation focused on “Positive Behavioral Supports” (PBS). Partnering with major universities and disabilities programs around the country, PBS initiatives developed a body of scientifically verified, accessible strategies for changing behavior and improving lives WITHOUT ANY NEED FOR NON-EMERGENCY RESTRAINTS OR OTHER AVERSIVES, even for clients with the most challenging behaviors. Conferences and trainings in these techniques continue to be held regularly throughout the country, a variety of web sites report on ongoing research, the *Journal of Positive Behavior Interventions* and a growing collection of books and peer-reviewed articles make this information widely accessible and easy to understand for professionals as well as families.

Positive approaches have been used effectively for many years

8. *Isn't it very difficult for a facility to stop using restraints as treatment? Don't providers need lots of time and money to make such a change?*

Other states have successfully eliminated aversives and non-emergency restraints

NO! Facilities all around the country have experienced great success in removing non-emergency restraint from their programs, which then became safer and more rewarding places both for clients and for staff. To offer one example, in 1997 Pennsylvania's system of nine state psychiatric hospitals made a commitment to massive restraint reduction, beginning with a ban on non-emergency restraint. The target for this change was a seriously disabled population experiencing frequent unexpected crises that often involved delusional, aggressive, and other challenging behavior. Staff members were re-trained in positive approaches, physicians were involved at once in any restraint use, and a publicly available reporting system tracked each hospital's progress, *all at no extra cost to taxpayers*. Incidents of restraint decreased by 90% and hours of restraint use by 95%, with some state hospitals now approaching zero incidence of restraint (for any reason) over the past year. This initiative won the Harvard School of Government's Innovations in American Government Award.

With the explosion of knowledge and effective innovations in the disabilities field over the last few decades, it would be disingenuous for any reputable modern service provider to claim that it "isn't ready" or "cannot do" what others across the country have already successfully implemented.

What are Restraints and Aversives?

Restraints are the forced restriction or immobilization of the body or parts of the body, including the perceptual and sensory systems. It is a human-induced traumatic stressor, causing excessive physiological stimulation that can overload the victim's internal and external coping mechanisms and alter developing pathways in the brain.

Restraint can lead to death, injury, or psychological trauma, and therefore is considered an acceptable risk only in an emergency.

In facilities for people with developmental disabilities and in behavioral day programs, restraints are used in emergencies (where the client may injure him/herself or someone else), or, in a power struggle between a direct caregiver and a client, to force compliance with staff commands.

Commonly Used Restraints

- Physical restraint: A broad category of restraints in which a patient's movements are restricted by the use of physical force.
- Mechanical restraint: A broad category of restraints in which a patient is immobilized through external devices such as straps, belts, wrist and ankle cuffs, or restrictive clothing such as straitjackets.
- Chemical restraint: the administration of incapacitating medications to control behavior by dulling and inhibiting movement and/or thought processes.
- Seclusion: When a patient is separated from the general population of a facility and not permitted to return at will. Typically, the person is placed in a designated room, which is often padded. The room is often locked but typically has observation windows or cameras so staff may watch.
- Two-point restraint: A standard mechanical restraint method. A device wraps around the waist and has straps or cuffs that go around the wrists to immobilize the arms.
- Four-point restraint: Another standard mechanical restraint method. The patient is placed on his back, typically on a bed. The wrists and ankles are strapped to the bed to immobilize the patient.
- Five-point restraint: Same as above, with the addition of a strap or a cloth device to restrict the patient's mid-section.
- Takedown: A broad term referring to a worker forcing the patient to the ground.
- Basket hold: A physical restraint in which a worker holds a patient from behind. The worker grasps the patient's wrists, and crosses the patient's arms across his or her chest. The worker then brings the patient to a seated position by stepping back and riding the patient down along the worker's thigh.
- Straitjacket: A coat-like device that is worn by a patient and used to bind his or her arms tightly against the body. Also known as a camisole.
- Floor hold: A broad term encompassing a number of physical restraints during which a patient is forced to lie on the floor.
- Facedown restraint: A broad term referring to a physical restraint during which the patient is facing the ground and staff members are either on top or beside the patient.
- Vest Posey: A vest that some facilities use during a bed or chair restraint. Posey is a leading manufacturer of restraint devices.
- Pelvic Posey: A cloth device that some facilities use during a bed restraint. The vest goes across the pelvis and keeps a person from wriggling out of arm and leg restraints.
- Cardiac chair: A padded recliner into which a patient is strapped. Often used in nursing homes. Also known as a geri-chair or restraint chair.

Aversives include, but are not limited to—

Aversives are the deliberate infliction of physical and/or emotional pain and suffering, for the purpose of controlling or conditioning behaviors deemed unacceptable (like hand flapping or refusal to sit in a chair) by teachers or behaviorists.

- Electrical Shocks
- Water Sprays
- Ammonia Inhalants
- Lemon Juice Squirts
- Tabasco Sauce in the mouth
- Slaps and Pinches
- Blindfolds
- Hair Pulls
- White Noise Helmets
- Isolation
- Withholding Food
- Rubber-band Snaps

Aversives include direct physical or corporal punishment; the temporary but significant loss of movement, perceptual, or sensory ability; the disruption of basic emotional equilibrium and sense of safety; and the ongoing loss of freedom or of pleasure.

Aversives may cause tissue damage, physical illness, severe physical and psychological trauma, and/or death. Behavioral programs using aversives focus only on the behavior itself, and do not consider the core issues causing the perceived unacceptable behavior. Aversives also ignore the neurological context of behavior, frequently targeting aspects of the disability that are not under the individual's control.

Practicing Restraint

The Child Welfare League of America

The Child Welfare League of America, one of the nation's most venerable and respected advocates on behalf of humane approaches to children and youth with challenging behaviors, has taken a strong stand against the use of restraints as "treatment." In *Practicing Restraint*, the cover article for the September/October 2003 issue of its publication *Children's Voice*, CWLA interviewed program directors and policy makers who have found better, nonviolent ways to help children and staff cope when problems emerge. Below are some thought-provoking excerpts from that story.

Restraints are dangerous

"Facilities that use seclusion and restraint have a much higher rate of injuries and sometimes deaths than institutions that don't use seclusion and restraint,"

The negative effects of restraint have been well-publicized in recent years, most notably in a 1998 series in the *Hartford (Connecticut) Courant* implicating restraint in the death of dozens of children each year.

"Facilities that use seclusion and restraint have a much higher rate of injuries and sometimes deaths than institutions that don't use seclusion and restraint," says Kevin Ann Huckshorn, Director of the Office of Technical Assistance for the National Association of State Mental Health Directors in Virginia. "Before the *Hartford Courant* expose, many people thought, 'We use restraint because we have to--it's a serious intervention that must be done well,' but now we're starting to ask why we're using restraint at all."

A culture of control

"There was a tacit belief that containing children, setting harsh limits, and imposing a physical restraint or seclusion was somehow therapeutic. How we got the idea that meeting a child's history with violence was somehow going to be palliative and restorative, we don't know."

If the *Courant* series revealed the lethal physical component of restraint, new research reveals the mental component is just as important.

"Children who are victims or witnesses to abuse experience significant changes in the way they regulate their emotions over time, creating all kinds of problems as they get older," Huckshorn says. And yet as these children escape violent, abusive surroundings, they are all too often subject to violence in a venue designed to protect them. "I think we've confused what's therapeutic in terms of intervention," says Janice LeBel, Director of Program Management for the Child and Adolescent Division of Massachusetts's Department of Mental Health (DMH). "There was a tacit belief that containing children, setting harsh limits, and imposing a physical restraint or seclusion was somehow therapeutic. How we got the idea that meeting a child's history with violence was somehow going to be palliative and restorative, we don't know."

Counteraggression: the fallout from restraints

"When kids were in trouble and in distress, the staff would set limits, and the kids would then become more agitated--a recipe for restraint."

If a child's past is the powder keg that makes potential conflict so explosive, it's often the staff who provide the spark. "In reviewing restraint episodes involving children, we noticed a pattern," says Nan Stromberg, Director of Nursing and Licensing for Massachusetts DMH. "When kids were in trouble and in distress, the staff would set limits, and the kids would then become more agitated--a recipe for restraint." "Research that looks at why restraint increases [stress] points to the phenomenon of counteraggression," says Paul Jones, Staff Development Coordinator at Home of the Innocents in Louisville, Kentucky. "When you feel like you're being attacked, there may be an [instinctive] reaction, and a staff member [may be contributing to that situation]. Counteraggression prevents people from being able to let those verbal assaults or other things go." "Everyone [is vulnerable to counteraggression], whether they admit it or not," Jones warns, "but the extent to which it happens decreases with experience and training."

Attitude is everything

"We grilled the directors,...looking at numbers of staff and training and how much they paid their workers, figuring there had to be some big difference that allowed them to be restraint free, but there wasn't one

At New York's Bellevue Hospital, where restraint is not used at all in the child unit, and only rarely in the adolescent unit, Stromberg and LeBel found a staff committed to doing whatever it took to see a child through a crisis by talking through the situation. "In the adolescent unit, we saw a remarkable example where a girl was very out of control, pounding the wall," Stromberg says. "Instead of offering the usual 'You've got to lower your voice and get in control,' the nurse manager was validating her anger, saying, 'I know you're angry, and that makes sense--I'd be angry too.'" The staff were able to escort the other children from the room, and in that quieter setting, the situation was quickly diffused. But to the DMH officials, it all seemed too simple. "We grilled the directors," LeBel says, "looking at numbers of staff and training and how much they paid their workers, figuring there had to be some big difference that allowed them to be restraint free, but there wasn't one. But there was crystal-clear, rock-solid leadership [committed to finding another way], and a group of people who understood they could negotiate any kind of crisis without resorting to restraint."

Eliminate secrecy

Accurate reporting is essential to reducing restraint use. In NJ, only emergency restraints are reported to state agencies. Restraints used as "treatment" (incorporated into a person's individual habilitation plan) are not.

Many agencies find the process of simply monitoring restraint more closely has a remarkable affect on its use. "Once you start measuring something, it's a pretty powerful tool to get people to start looking at their actions," says Steve Karp, Chief Psychiatric Officer for the Pennsylvania Department of Public Welfare. "When we throw a graph up on the wall, [staff at one hospital] can recognize they're not doing as well as some of the other hospitals, and that really motivates them to bring their numbers down. There was a decent disparity among hospitals initially, but now they're all very successful because the ones that weren't doing so well communicated with the others and asked what they were doing to get their numbers down." When a physical intervention raises a red flag, people think twice before choosing restraint. Karp and others say making people accountable for such decisions forces them to ask, "Is this really worth the trouble?" Of course, management needs to show the new approach is designed to help residents, not punish staff.

Restraints are costly

Sure, [training new approaches] is labor-intensive, but restraints are too, and they usually happen when you least want to invest that time.

A big part of that philosophical change must come from the leaders of the organization. Several people interviewed for this article have seen agencies try to make changes, only to have the leadership end the process. "If you don't have 100% buy-in from management, you're wasting your time," Jones says. "That's why senior managers, even CEOs, should get the same training as staff, so they know firsthand what's expected." But motivation isn't always enough. It's easy to tell staff not to restrain residents, but unless you provide alternatives, you're unlikely to change their actions. As one supervisor noted, "If the only tool in your toolbox is a hammer, you'll treat everything like it's a nail." So how do you increase the selection of tools with a limited amount of time and an already overworked staff? "These kids require your time one way or the other," (Brian) Farragher (Director of Campus Programs for Julia Dyckman Andrus Memorial in Yonkers, NY) says. "You can either give it, or they'll take it. Sure, [training new approaches] is labor-intensive, but restraints are too, and they usually happen when you least want to invest that time. These kids are complicated; they're not so easy to figure out. Restraint takes a lot of brawn, but not a lot of brains. Sometimes, it's easier to use restraint than to think through a situation and figure out how to avoid it."

Reducing staff turnover

"Instead of functioning as custodians and police, staff have been elevated to be teachers and role models."

The move away from physical restraint may have an unforeseen positive effect on workforce retention and turnover. "We recruit a lot of kids out of college ... who don't think of this work as rolling around on the floor wrestling with kids," Farragher says. "The work they want to do is more cognitive. Turnover is exacerbated by an environment with lots of restraints. Our retention has improved dramatically over the last couple of years, and the fact that staff aren't wrestling with kids every day is a contributing factor." Stromberg agrees. "Instead of functioning as custodians and police, staff have been elevated to be teachers and role models."

Violence does not teach self-control

"If you're looking at facilitating the growth or rehabilitation of kids ..., and you're trying to make them productive adults, you don't do that by forcing, coercing, controlling, and ruling them,"

"[In] any residential environment where people are being treated in an institutional sense ... the traditional culture is characterized by control," Huckshorn says. "The mantra has been when you have a large group of people in [your care], you need to control them ... That's extremely conducive to using violence to make people do what they think they should do." "If you're looking at facilitating the growth or rehabilitation of kids who've already been traumatized and haven't had good role models, and you're trying to make them productive adults, you don't do that by forcing, coercing, controlling, and ruling them," Huckshorn says. "If you include the people in your facility in some of the decisions, give them some choices, and allow them to make some decisions, you have much less conflict." "All models of recovery are based on empowerment, self-determination, collaboration, partnerships," Huckshorn adds. The more control an agency yields to its residents, the more opportunity for growth." Odds are any approach to lowering restraint will also improve conditions on every level as children begin to see staff as supportive agents rather than potential adversaries. "Our agency is a kinder, gentler place--and these places have to be safe, because kids come here with multiple traumas, where people who were supposed to take care of them hurt them," Farragher says. "There's a real pull to use physical force because of the way some of the kids behave and some of the issues they bring in, but we've lost the sense that we need to control the kids--the kids are encouraged to control themselves."

Becoming proactive instead of reactive

Those who cling to restraint as a valuable practice generally cite one potential problem with other approaches: What do you do if a child poses a serious danger to himself or others? "Whoever is asking the question hasn't thought ahead,"

Those who cling to restraint as a valuable practice generally cite one potential problem with other approaches: What do you do if a child poses a serious danger to himself or others? "Whoever is asking the question hasn't thought ahead," says Janice LeBel, Director of Program Management for the Child and Adolescent Division of Massachusetts's Department of Mental Health (DMH). "When you get to the point where somebody is self-harming, you've lost the chance to intercede early, to respond to the triggers that preceded that self-harming behavior." "Behavior does not come out of the blue--it's triggered by something," adds Nan Stromberg, Director of Nursing and Licensing for DMH. "To work with a child and the parents to identify those triggers [beforehand], you need to plan and identify some actions that will help if the child gets upset--maybe coloring, maybe being in a rocking chair, being held, playing a game, telling jokes." LeBel cites a push in Massachusetts for providers to adopt a public health approach. "The primary component is doing all your frontloading--thinking, planning how to avoid the use of physical intervention, and creating policies and procedures that can mitigate the need for restraint. The second component involves looking at the tools: Do we have the tools? Are they being used? Are they being incorporated into treatment plans? And lastly, if something untoward does happen, the third stage allows you to debrief: What happened? What went wrong? What can we learn? And it feeds right back into the process of retooling your whole system."

Restraint and Segregation

New Jersey's Vicious Circle

- Out-of-district segregation of school-aged children with disabilities is increasing in New Jersey alone, of all the 50 states.
- Twenty-eight years after the passage of the federal law guaranteeing children with disabilities the right to an education with their non-disabled peers, New Jersey is almost alone among all states in supporting the continued construction of separate public education facilities.
- Six new segregated private special education schools have been approved by the New Jersey Department of Education since 2000-2001.
- New Jersey sends a far higher percentage of children to out-of-district separate education schools -- three times higher than the national average -- than any of the other 49 states and the territories. Only the District of Columbia is worse.
- More than 90% of the funds New Jersey districts receive to assist in the payment of services for children whose special education costs exceed \$40,000 a year is being spent on out-of-district placements rather than to support the child in-district.
- New Jersey is second in the nation (after Alabama) in the number of adults who end up in institutional settings rather than living and receiving services in their own communities.
- Serious injuries at New Jersey's seven state institutions have risen at a rate of over 50% during the past five years.
- New Jersey is one of the only states in the nation facing federal sanction, which could cause the state to forfeit tens of millions in aid, due to the levels of abuse and neglect in its state institutions.

AND YET....

- Certain New Jersey legislators are trying to pass a bill (Substitute Bill A205), which would protect the rights of private facilities operating on public funds to use restraints and aversives as "treatment" for people with disabilities.
- Restraints and other aversives are considered abuse when used by parents in public places. Schools do not use them on non-disabled students because state statutes prohibit corporal punishment. Restraints and aversives are prohibited in Community Care Homes for children and adults with disabilities because they violate community sensibilities. They cannot be used as treatment on prisoners, on elderly residents of nursing facilities, or even on pets.
- The use of restraints and aversives must be hidden away, out of view from the general public and from the authorities, because it offends public standards of decency and conflicts with statutes concerning abuse and corporal punishment. **Therefore, the children and adults on whom restraints and aversives are used must be kept out of sight.**

RETURN TO THE TOP OF THIS PAGE AND READ AGAIN TO COMPLETE THE VICIOUS CIRCLE.....

Prepared by *The Family Alliance to Stop Abuse and Neglect*, with thanks to SPAN, the Statewide Parent Advocacy Network, and NJCIE, the NJ Coalition for Inclusive Education

The Double Standard

What is easily recognized as child abuse in the community is called “effective treatment” for children with developmental disabilities and traumatic brain injury in New Jersey.

When children without disabilities are abused and/or neglected in the community, the public is outraged. The criminal justice and child welfare systems spring into action. People are held accountable for their actions.

- **“She's whacked!! She's crazy!!”** That's the way outraged neighbors here in Bristol Borough are describing 22-year-old Danielle Raab after police made their shocking revelations. Police say Raab and her boyfriend, 27-year-old Russell Gillespie, abandoned their toddler and wrapped her in duct tape to keep the child from taking off her diaper. Worse, that they hitched her to a harness confining her like a prisoner in her room.

(WPVI Ch. 6 News, October 1, 2003)

- Officer Barry Davis said that when he arrived at the home about 8:30 p.m. Aug. 30, he found the child alone, sleeping in bed with a red nylon harness secured to her body with duct tape. The harness was attached to the bed. “The tape was stuck to her skin, and the skin under her arms was raw,” Davis said yesterday. **“It was a shock to me that somebody would do that to their child.”**

(Philadelphia Inquirer, October 2, 2003)

When adopted, fostered, or biological children are abused and/or neglected, caseworkers are fired, criminal charges are filed, and Congressional hearings are convened. When children with disabilities are abused, neglected, or even killed, no one is held accountable.

Foster/Adopted Children

The Jackson Case

- “Mr. Sarubbi has charged the boys' adoptive parents, Raymond and Vanessa Jackson, with **aggravated assault and child endangerment** in the case. “

(NY Times 11/7/03)

- “A congressional committee will join the investigation into the case of a Collingswood couple accused of starving their four adopted boys over a period of years.”

(WCBS Radio 880, 11/1/03)

- “Nine employees of the state Division of Youth and Family Services were fired Monday, the latest casualties in what officials called the **worst case of child neglect they have ever seen.**”

(Courier Post 10/28/03)

Children With Disabilities

Matthew Goodman

- “After a thorough investigation and complete review of all the facts of the case, we have concluded that there is **insufficient evidence of criminal conduct** to warrant the filing of criminal charges against Bancroft or any individual employee,” Prosecutor Vincent P. Sarubbi said in a prepared statement yesterday.

(Star Ledger, 1/3/03 re: Camden County Prosecutor's investigation of Matthew Goodman's death.)

- Disagreeing sharply with another state agency's findings, the New Jersey Division of Youth and Family Services has concluded that Bancroft NeuroHealth's care did not cause the death of a Bucks County autistic boy. Last year, the state Division of Developmental Disabilities found that Matthew Goodman, 14, of Buckingham, had suffered abuse and neglect at the facility before he died Feb. 6, 2002, at Children's Hospital of Philadelphia. But in a recent letter to his family, DYFS concluded that **“none of these concerns contributed to Matthew Goodman's decline or death.”**

(Phil. Inquirer 2/14/03)

When adopted, fostered, or biological children are abused and/or neglected, we hear that government has an obligation to protect them. When people with disabilities are abused and/or neglected, even when they die, we hear that government must protect the “industry” that “serves” them.

Community

- “Government will never love a child the way his or her family must. But when those families cannot or will not provide that love and attention, **government has a fundamental moral obligation to protect children.**”

(Kevin Ryan, before the Subcommittee on Human Resources, House Ways and Means Committee, November 6, 2003)

- “It’s inconceivable how a case worker could go there and not detect these atrocious conditions,” New Jersey Gov. James McGreevey said. **“People who made bad decisions will be held accountable.”**

(NY Newsday.com, 10/27/03)

NJ Facilities

- “David Holmes, president of Eden, a Princeton-based nonprofit group that provides care for autistic children and adults, said that **Danielle’s Law would cripple “an industry already at risk.”**

(Windsor-Hights Herald, October, 2003)

- “Dr. David Holmes, president and chief executive officer of Eden Institute, which provides educational and transitional services for people with autism, said that, on the contrary, the new legislation will cause turmoil for already burdened professionals and agencies. ‘It will create chaos in the system,’ Dr. Holmes said. ‘Every time you have a snuffle, you’re going to have people calling 911. We’re **creating too many laws that create too much exposure and too much risk for agencies already at risk as it is.**’”

(Princeton Packet, October 2003)

Precipitous weight losses in fostered, adopted, or biological children are recognized as obvious signs of neglect. Similar weight losses in children with disabilities trigger no response.

Foster/Adopted Children

The Jackson Case

- “They're either incompetent, uncaring, or they lied,” Gwendolyn L. Harris, commissioner of the state Department of Human Services, said on Monday, adding that “**any reasonable person**” would have recognized something wrong with the brothers.

(Phil. Inquirer, 10/29/03)

- Mr. Sarubbi said his accusations were backed by medical evidence. “We enlisted medical experts to evaluate the boys' condition,” he told the Human Resources Subcommittee of the House Ways and Means Committee. “These medical experts determined that the **boys had been deprived of adequate nutrition and medical care**. Based upon these medical assessments and other investigative information developed, I was satisfied that probable cause existed to support criminal charges.”

(NY Times 11/7/03)

- Among those fired was a caseworker who made monthly visits to the Collingswood home of Raymond and Vanessa Jackson, who authorities say fed their four adopted boys a **diet of pancake batter, cereal and peanut butter and jelly**.

(Courier Post 10/28/03)

Children with Disabilities

Danielle Gruskowski

Matthew Goodman

- “When I was there, I had to train staff, I could never just visit and enjoy my daughters company otherwise she may have gone without a meal or a drink that night or not get repositioned in her chair. Night after night at the facility I had to bring all my concerns to their attention such as her **significant weight loss of 25 pounds** otherwise it would have gone unnoticed.”

(Diane Gruskowski, testimony 6/9/03 Note: Danielle's weight dropped from 105 lbs to approx 78 lbs while she lived at Spectrum's facility.)

- Matthew Goodman died from aspiration pneumonia, acute respiratory stress, and a blood infection the day after he became unconscious and was driven by Bancroft employees to Children's Hospital. His mother pointed to the rapid decline in Goodman's health - he **lost 23 pounds** the weeks before he died.

(Phil Inquirer, 2/14/03)

Children who are isolated from their communities are at greater risk of harm than those who are not. NJ leads the nation in the percentage of special needs children who are educated and/or housed in segregated settings. We are the only state that is still building new segregated buildings in which to warehouse children with disabilities far away from their non-disabled peers, homes, and communities. We are second only to Alabama in the percentage of adults with disabilities who are living in institutions.

Foster/Adopted Children

The Jackson Case

- One of the problems that we have already identified in the Collingswood case is that the children ***were isolated from the professional community.*** It appears the children were never taken to a doctor for a medical exam and because they were home schooled they were never seen by teachers on a daily basis as most children are.

(Colleen Maguire, Deputy Commissioner of Human Services, testimony at Congressional Hearings, 11/6/03)

Children with Disabilities

Matthew Goodman

- In September of 2000 Bancroft placed Matthew in arm restraints, later adding a helmet similar to a hockey mask. Against the protests of his parents, Matthew was made to wear these restraints during the day and often during the night. ***He no longer was taken to school, saw no friends, enjoyed no recreation, and was offered no activities or programming.*** In addition to the mechanical restraints Matthew was drugged with medication. He spent his days lying on the floor of Bancroft's "NeuroHealth unit," barely conscious.

(Pat Amos, The Family Alliance to Stop Abuse and Neglect)

What's the Difference?

SPAN Testimony at DYFS Reform Plan Hearings

March 2003

On behalf of the Statewide Parent Advocacy Network of New Jersey, Inc. (SPAN), thank you for this opportunity to comment on the proposed plan, "A New Beginning: The Future of Child Welfare in New Jersey," an effort to comprehensively reform New Jersey's child welfare system.

What is SPAN?

SPAN is a statewide organization dedicated to empowering parents and concerned professionals to work together to maximize the healthy development and achievement of New Jersey children, birth to 21. Our motto is "Empowered Parents: Educated, Engaged, Effective!" We provide information, training, technical assistance, family support and strengthening, leadership development, and advocacy for families, with a special focus on children at greatest risk due to poverty, disability, discrimination, immigrant status, family circumstances, and other factors. We are the Parent Information & Resource Center under No Child Left Behind; the Parent Training & Information Center for parents of children with special needs; a chapter of the Federation of Families for Children's Mental Health and Family Voices; and house NJ Statewide Parent-to-Parent. We were co-founders of the Children and Family Initiative, which led to the development of the Children's System of Care/Partnership for Children with special emotional/mental health needs. Through our Community Education Project, we provide direct support to families whose children are involved in violence, substance abuse, special education, juvenile justice, DYFS, and other systems. Through our Parent-to-Parent project, we match families in crisis with trained mentor "support parents." Through our Violence Prevention Project, we facilitate family strengthening programs such as Strengthening Families and Strengthening Multi-Ethnic Families & Communities and work to improve social problem-solving programs and violence and bullying prevention and intervention in schools across the state. We work with families comprehensively, across systems. Thus, we are concerned with multiple systems that are involved in child welfare, safety, and protection, from the Department of Human Services to the Departments of Health & Senior Services and Education.

Our comments on the proposed changes to New Jersey's "child welfare system" are based on our direct experience with families as well as our long history of advocacy on behalf of New Jersey's most vulnerable children and expertise in "systems change."

The proposed plan is not comprehensive.

While a review of the proposed plan reveals the potential for a much stronger child protection and abuse prevention system, it is **not** a *comprehensive* plan. It is merely a framework that reorganizes the Department of Human Services, creates a new Division of Children's Services and Division on Prevention and Community Partnership, and makes a link between the needs of families under state Division of Youth and Family Services supervision and housing and substance abuse programs. As the state's Child Advocate, Kevin Ryan, notes, reforming DYFS, or even the Department of Human Services, is not sufficient to ensure that New Jersey children are safe from harm; the

most effective strategy towards that end is to strengthen New Jersey's families and provide them with the supports they need to effectively and lovingly raise their children.

The DYFS situation has gotten worse.

Despite the attention that has been paid to DYFS over the past several years, foster children actually suffered more instability in 2003 than in previous years, according to the recent report of the Association for Children of New Jersey. A greater percent of children moved from home to home and were placed outside their home counties, and siblings in care were more often separated. There was also a 33% drop in the number of adoptions finalized in 2003, primarily because adoption workers were dispatched to perform other reform-related tasks. The state's proposal to fold the Adoption Resource Center staff into district offices could threaten New Jersey's past progress in placing children in permanent, adoptive homes.

SPAN supports the elevation of children's services envisioned by the plan, as well as proposed steps to more effectively coordinate services. But unfortunately the plan does not effectively engage and involve the other systems that affect children – health, education, juvenile justice – and so it is doomed to failure.

A major shift in attitudes is required.

SPAN also supports the plan's call for more caseworkers and reduced caseloads, and its approach of involving families more closely in solving problems and creating plans for their children. But it will require a major cultural shift in the way that caseworkers, supervisors, service providers, and families themselves operate. Merely telling caseworkers to adopt a certain attitude – or even a particular practice – is insufficient. For example, despite the requirement that children with disabilities in the DYFS system have "surrogate parents" to make educational decisions for them, far too often DYFS staff continue to illegally sign consent for evaluations, IEPs, and placements. How will DYFS staff become competent in their new roles, the new approaches mandated by the plan, and their relationships with families and communities? The state has not done a credible job in the Partnership for Children with mental health needs in changing the attitudes and behaviors of professionals working with families – how will this be any different?

Major Concerns...

SPAN shares many of the concerns expressed by ACNJ and other advocacy organizations:

- How will the plan ensure that the new "one worker/one family" model does not assign too many conflicting tasks on caseworkers?
- How will the plan ensure a strong foster care and adoption system for children who are unable to remain with their birth families, or be reunited with them?
- Where is the accountability? Who has final responsibility for ensuring child safety? How will the division be held publicly accountable for its responsibility and new roles? How will the information from the improved data collection system be used to

inform and engage the public?

- How will civil services, supervisory/management, and union issues that have to date blocked implementation of reform efforts be addressed? The plan fails to mention these concerns, which were publicly discussed a year ago by Governor McGreevey as issues that prevent the division from effectively managing its workforce. More support for caseworkers is critical, but not sufficient; DYFS must be able to quickly (and fairly) remove caseworkers who are not doing their jobs well.

The plan does not consider children with developmental and mental health issues.

In addition, as an organization that works with families who are forced to “give up” their children with mental health concerns in order to get the services their children need, and families whose children with developmental and mental health issues are locked away, restrained and abused, in our state’s public and private institutions (often subject to DYFS “oversight”), we are disappointed that the plan totally eliminates consideration of the responsibilities of the state in ensuring that these children as well are safe and secure.

Double Standard

There is a double standard in our state – much attention is paid to families who, for a variety of reasons, might abuse or neglect their children. But little or no attention is paid to our own state-run, state-approved, and/or state-monitored institutions that abuse and neglect children through the use of aversives and restraints.

Foster care and adoption are not the only settings in which children with special needs are served.

The most devastating weakness of New Jersey’s current “child protection” system is the unpredictable, uncoordinated patchwork of protections and expectations covering the various settings that provide services to our most vulnerable children. Large numbers of children who enter foster care have disabilities, either from birth or resulting from circumstances in the child’s early environment, which precipitated the events leading to foster care or adoption. This is also the population likely to become eligible for Federal adoption subsidies and related services. Foster care and special needs adoption are generally administered by the state agency or division responsible for youth and family services — in New Jersey, DYFS. However, *foster care and adoption are not the only settings in which these children are served.* They may be placed in privately run but publicly funded residential facilities for children with disabilities, in state institutions or “developmental centers” for individuals with mental retardation, or in children’s mental health facilities.

DYFS might remove children from homes where they were forced to ingest noxious substances, and then place them in a facility where forced ingestion of noxious substances is part of their habilitation plan!

For no good reason, protections vary widely among these settings. In New Jersey, DYFS would be expected to intervene in a home in which a child is being routinely subjected to physical or mechanical restraints (immobilizing arms or legs) or to punishments such as slapping, forcing a child to spend hours in a blindfold, or forcing a child to inhale or swallow noxious substances. But DYFS is also expected to monitor the well-being of these same children in private and public residential settings where such activities are incorporated into their Individualized Habilitation Plans (IHPs). This is a clear double standard that is nevertheless sanctioned in the regulations of the state Division of Developmental Disabilities (DDD). Thus it would be perfectly possible for DYFS to remove a child from a home where, for example, he is being disciplined via forced ingestion of noxious substances, and place him in a facility where forced ingestion of noxious substances then becomes part of his habilitation plan.

DYFS' findings illustrate the double standard that sanctions abusive and neglectful "treatment" in select settings.

During the past year DYFS has been required to investigate harm to children with disabilities, including the death of a 14-year old boy left on the floor of a private residential facility in arm restraints and a helmet for 16 months, until he developed severe pneumonia and sepsis. We believe that DYFS' finding of "no neglect" in that case and several others was due to the double standard which sanctions abusive and neglectful "treatment" *in select settings*. Like the boys recently removed from their Collingswood home, this 14-year old child was neither attending school nor was his condition investigated or questioned by the school district. A precipitous weight loss of 25 pounds in the last weeks of his life went unreported and untreated. While such conditions would create a scandal if discovered in a foster or adoptive home, they do not seem to trigger a response when discovered in a residential facility. In fact, according to its 2003 budget DYFS is still paying for at least one other child under its care to reside in this same facility (which has lost its accreditation from the Commission on Accreditation of Rehabilitation Facilities, or CARF) at a cost to taxpayers of nearly \$1000 per day. To add a final twist to this tale of grossly inequitable protections, had this young boy been placed in a children's health care facility covered by the Federal Children's Health Act of 2000, the restraints which led to his decline and death would not have been permitted.

The facilities are run by profitable corporations, with the means and motive to engage lobbyists, public relations staff, attorneys, and others to protect them from unwanted regulation and scrutiny.

Children who are placed in congregate, facility-based care should be presumed to be in *greater* danger than children in foster or adoptive care for two critical reasons. First, these children tend to be far more segregated from their communities, making it less likely that caring friends, relatives, or members of the general public will observe and respond to indicators of abuse and neglect. The more a facility relies on restraints and aversive punishers as part of its clients' "habilitation" plans, the less it will be willing or able to take those clients into public places where such activities on the part of staff offend public sensibilities and have been known to trigger calls to the police. A vicious cycle of unobservable mistreatment is set in motion. Second, these facilities are run by profitable corporations, which have the means and motive to engage a panoply of lobbyists, public relations staff, attorneys, and others to protect them from an unwanted degree of regulation and scrutiny. Individual families do not have such resources

available to keep oversight and accountability at bay (although the recent Collingswood case is notable for the family's attempt to confront its problems as many corporations do).

A number of private service providers have blocked efforts to protect children with disabilities.

The Family Alliance has repeatedly tried to introduce regulatory and statutory protections for New Jersey's children with disabilities, hoping to keep them safe wherever they may live. In the name of "protecting the industry" from "too much regulation," a number of private service providers have blocked these efforts. The legislature and the state agency have now decided that they will not move on residential reform until they receive a clear message from the Federal government, in particular through the new regulations due out this Spring for Intermediate-Care Facilities for the Mentally Retarded (ICFs/MR) which govern many of the state and private facilities in which children are placed.

We need to guarantee equal protections to all vulnerable children, regardless of the setting.

As we have said from the beginning, the panel should have broadened the scope of its work beyond family placements to the other federally funded settings in which this population of children can be found. Across the range of foster care, subsidized adoption, private and state residential facilities for individuals with mental retardation and developmental disabilities, and mental health facilities, we find the *same children*. Until we develop statutes and regulations that guarantee equal protections to all vulnerable children regardless of the setting in which they reside, mixed messages, segregated and virtually invisible residential populations, and differential tolerances for abuse and neglect will continue to permeate State agencies such as DYFS, and to make monitoring and enforcement efforts confused and problematic.

Workers have abused their young charges and exposed them to serious injury.

As noted in a newspaper article in the Bergen Record last year, "Workers who serve as the last line of defense for troubled children have abused their young charges and exposed them to serious injury, including a broken arm and permanent paralysis. Documents show widespread problems at state-licensed group homes and residential treatment centers, including failure to provide even minimal supervision, having inexperienced and poorly trained staff, and using overly aggressive methods to restrain children who act up. Some workers can't control their own tempers, and curse at and punch the youths they're paid to help. These findings are the latest in a series of revelations about New Jersey's beleaguered child welfare agency. The Record reviewed state inspection reports for 30 state- and privately run programs and found a range of problems -from hiring staff with criminal backgrounds without state permission, to employees sleeping on the job and improperly dispensing medication..."

Families who want to keep their disabled children at home are excluded.

Unfortunately, too often children end up in these institutional placements because the state does not provide the support that families need to keep their children with mental health and/or developmental disabilities at home. How can the state develop a "comprehensive" plan that excludes the supports these families need – families who are NOT abusing or neglecting their children, but who cannot get the services their children need and the supports they need without placing their children in an institution, and then find out that the institution is abusing and neglecting their children?

Expand the plan.

SPAN urges the state and the panel to take another look at their plan and to expand it to address the issues faced by these families and their children. Without including this population of at-risk children, the plan cannot be a strong blueprint for reform of the child welfare system.

Conclusion

In conclusion, SPAN welcomes the proposal as a positive first step in strengthening families and improving the lives of New Jersey's most vulnerable children. However, it is not the comprehensive and coordinated plan that we need to make sure that all New Jersey children are safe, secure, and loved.

Finally, we would like to take this opportunity to raise serious concerns about the lack of time that has been provided to the public, parents, and advocates, to review this quite long and complicated plan, analyze its contents, and develop thoughtful comments and suggestions for improvement. It is unrealistic, shortsighted, and disrespectful to allow so much time to be spent developing the plan, with very limited public input or information, and then allow so little time for thoughtful consideration of the plan by those in the communities that the plan is intended to serve. Is this how families will be involved in the future? If so, expect family participation to be minimal and not very effective. We urge you to extend the time for public comment on a plan of this magnitude and importance to our state, our communities, our families, and our children.

*Diana MTK Autin
Executive Co-director
Statewide Parent Advocacy Network*



Steering Committee:

TASH

National Association of
Protection and Advocacy
Systems

Family Alliance to Stop
Abuse and Neglect

Bazelon Center for
Mental Health Law

Federation of Families
For Children's Mental Health

National Down
Syndrome Congress

National Association of
Councils on Developmental
Disabilities

National Down Syndrome
Society

Autism National Committee

The Arc of the United States

The RespectABILITY Law
Center

VISION

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

For Information about this issue and the Alliance

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A.P.R.A.I.S. APRIL 16, 2004 – PRESS RELEASE

Members of the nation's leading education, research and advocacy organizations announce the creation of a powerful new initiative to protect children from abuse in their schools, treatment programs, and residential facilities. The Alliance to Prevent Restraint, Aversive Interventions, and Seclusion is responding passionately to the increasing toll of deaths, injuries, and trauma resulting from the use of inhumane practices in programs serving children and youth with disabilities.

"We have been patient for too long," said Kathleen Gee, President of TASH, an international membership organization advocating for inclusion through best practice based on research. "Every day in this country, vulnerable children with disabilities are being brought down to the ground and straddled by program staff, slapped and pinched, deprived of food, secluded in locked closets and more. Amazingly, these abuses are often considered part of children's education and treatment plans, and are carried out by the very adults entrusted with their care, protection and development. If parents used restraints and aversive procedures in their homes as some schools and service providers routinely do, they would face criminal charges and lose custody of their children."

Members are particularly concerned about the persistence of aversive interventions, restraints and seclusion in children's programs and are dismayed by the convoluted and often contradictory tangle of state and federal regulations that address these dangerous activities. "There is no equal protection for our children with disabilities, and parents become very confused about what their rights are," says Janice Roach, parent of a young man who died after 16 months of restraint and denial of appropriate education and treatment. "It makes a big difference which state you live in and which funding stream serves your child. In my child's case he started school in a state in which restraint was prohibited, was then sent to a neighboring state in which restraint was allowed, and subsequently died. Parents assume that the same rules requiring humane treatment apply everywhere, but they don't."

The new alliance is responding to this concern by working together to identify the laws, regulations, and loopholes that permit the use of aversive interventions, non-emergency restraints and seclusion. In addition, alliance members are preparing information that will assist families to know their rights and how to protect their children. A database of individual stories will be gathered and shared, and informational events of national significance are planned. Trina Osher of the Federation of Families for Children's Mental Health states, "We believe the nation has reached a tipping point on this issue. There are many wonderful programs around the country serving children with the most complex disabilities and behavioral challenges in non-punitive, non-coercive settings. Research and experience have clearly demonstrated positive approaches work. It is time to assure that that no child grows up afraid and abused by the very people and programs that are supposed to provide education and treatment."

N e w s R e l e a s e

**FAMILY ALLIANCE SCHEDULES
“LUNCH + LEARN” FOR NJ LEGISLATORS**

FOR IMMEDIATE RELEASE

Contact: Victoria Horrocks
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Trenton—The Family Alliance to Stop Abuse and Neglect is inviting New Jersey Legislators to “drop in, have a quick lunch, and learn from NJ providers about modern, positive methods of addressing the core issues of people with developmental disabilities—without using aversive punishers or non-emergency restraints.”

The “Lunch + Learn” session will be held on June 17 in Committee Room 3 at the State House Annex from 11:30 am to 2:00 pm. The list of exhibits will include Positive Behavior Supports, the DIR (Floortime) Model, and some of the specific therapies that are often part of successful programs—Speech/Language, Sensory Integration, Auditory Integration, and Interactive Metronome. “Behavior is the symptom, not the problem,” says Mary Kientz, occupational therapist and director of All in a Day’s Play. “Instead of focusing on surface behaviors, modern methods strengthen key processing abilities in communication, sensory processing, and motor planning and sequencing so that people with developmental disabilities can regulate their own behavior.”

Robin Turner, of the Family Alliance, said, “We understand that some NJ Legislators have been convinced by a few special interest groups into believing that aversives and non-emergency restraints are necessary when providing services to people with developmental disabilities. They’ll get a chance to discover first-hand that they’ve been misled.”

The Family Alliance is a group of volunteers whose mission is to stop abuse & neglect, create positive system-wide changes, and promote best practices to guarantee the human rights and dignity of people with disabilities of all ages.

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