

A Short History of Aversives in Massachusetts by: Polyxane S. Cobb

Introduction

People with severe behavioral problems, who may be aggressive or self-abusive, and who have profound difficulties learning to control their behaviors have long been a challenge. Over the years people have developed theories exploring what the contributing factors might be in the expression of these behaviors. Often, however, the sources have remained obscure and the methods to correct them have remained elusive.

Many purported therapies have been developed that promise the elimination of these behaviors. Some have been rigorously tested and then shared in detail within the profession through articles in scientific journals and, therefore, held up to the scrutiny of peer review. Others remain unpublished promises—perhaps presented verbally at conferences. “Aversive Therapy” is in the latter category. Its most extensive use began at the Behavior Research Institute (BRI) in California. Following a series of lawsuits by private clients as well as the State of California, BRI moved its operations to Rhode Island. Because many of the residences attached to the school were located in Massachusetts, the facility needed to have a license in Massachusetts.

The Office for Children (OFC), then the licensing agency for all programs effecting children in Massachusetts, tried to suspend the use of aversives at the program. BRI went to probate court in Bristol County, complaining that without the use of these procedures their clients would either permanently injure themselves or even risk death. The commonwealth maintained that only the OFC had jurisdiction to permit the use of aversives. It therefore did not present opposing arguments to the BRI contentions. The court ruled in favor of BRI.

In the 1980s and 1990s BRI regularly went to the same courtroom, presided over by Judge Ernest Rotenberg to request substituted judgement decrees for the use of various aversive procedures on its students. They were usually successful. Following its move from Rhode Island to Canton Massachusetts, BRI changed its name to the Judge Rotenberg Center (JRC).

BRI (JRC) in Massachusetts

BRI used techniques that involved slaps, spansks, pinches, restraints, noxious substances sprayed into the face and nostrils, and a long list of other so-called therapies over the years.

In 1992 BRI reported that it had abandoned them in favor of a single device, the GED

(graduated electronic decelerator), food deprivation, and restraints. All three, to this day, are represented in the Individualized Service Plans (ISPs) of the students at JRC. The GED is subject to regulation by the Food and Drug administration. BRI did not, however, apply to the FDA for review and approval to use the GED until late in 1994. The FDA has since given BRI permission to market the device as being substantially like another approved device (the SIBIS), but the GED does not have FDA approval and BRI/JRC may not state that it does.

There have been instances of the devices misfiring—set off by passing cellular phones or other malfunctions. There has, as well, been documented instances of staff error. More disturbing, on about a third of the students against whom this device is used, burns of the skin, some reaching the blister stage (second degree burns), have occurred. The jolts these children and young people experience are not the short, explosive shocks one might receive from a discharge of static electricity on a cold winter day. The device is activated for a full two seconds. Over the years the amperage has been increased as the students acclimated to the jolts and they lost their “effectiveness.”

BRI/JRC: Its History Of Changing Therapies & Five Deaths

BRI/JRC has promoted the use of severely invasive behavior modification for many years. It has always been controversial. Besides electric shock which, along with restraints and the denial of food are the procedures JRC maintains it uses at present, they have also used ammonia sprays, automatic vapor spray stations [*a phone-booth like box that restrains a client and forces him/her to endure automatic sprays in his/her face of water or other substances*], slaps, spanks, deep muscle squeezes, hot peppers on the tongue, and other painful invasions.

Some events from the history of BRI/JRC:

1980 Robert Cooper, a 25-year old student at BRI, dies of a bowel obstruction caused by the twisting of the bowel. BRI is exonerated in the death but is criticized for transporting the young man to the hospital by private vehicle rather than having an ambulance speed him there. Why the school failed to seek treatment for the young man until the obstruction had become lethal is not known, but the same kind of fatal delay occurred more than ten years later when another student (see below) succumbed to peritonitis from a perforated ulcer.

1981 Danny Aswad, a student at BRI of California, died while in restraints that kept him flat on his stomach. The time of death is uncertain—between 9:00 am and

10:00 am—because during that full hour in restraints he was not monitored. Remarkably, the county coroner ruled the cause of death to have been “mental retardation” and “cerebral malformation” neither of which have been shown to have been lethal conditions.

1985 Vincent Millitich a student at BRI [Rhode Island] dies while being punished for “making inappropriate sounds” while at his group home in Seekonk, MA. Millitich’s death occurred while being shackled, fitted with a helmet emitting white noise, his head forced down between the knees of a staffer. Millitich dies of asphyxiation according to the medical examiner.

1987 Abigail Gibson, a student at BRI suffers a heart attack and dies. Her treatment plan of spanking, pinching, and cold water showers was approved only three days prior to her death.

- Massachusetts court cites Matthew Israel for negligence in the death of Vincent Millitich along with two physicians connected to BRI for approving the white noise therapy for the young man who had a history of seizures.

1990 Linda Cornielson, a student at BRI, dies of a perforated ulcer after two days of acute illness. Her punishments increased dramatically over the two days prior to her death on December 18th—more than 57 being administered in the last four hours before an ambulance was called while she was in one of BRI’s group homes located in Massachusetts. Her death was not reported by BRI to the Department of Mental Retardation as required by regulation even though DMR is the licensing agent for Massachusetts. DMR received notification of the death in late 1993 when the girl’s mother brought a suit for negligence. [BRI maintains that a phone call the next day to a regional office of DMR constitutes sufficient notification.] An extensive DMR/DPPC investigation which followed found that Cornielson’s treatment was “inhumane beyond all reason” and violated “universal standards of human decency.” In 1995 JRC was found negligent in the death of Linda Cornielson.

1994 August -The State Auditor attempts a full audit of certain financial practices of BRI to determine whether the expenses in three areas were charged against state contracts appropriately. BRI, claiming attorney-client privilege refused to provide the documents required of them by the State Auditor, even though state contracts require entities such as BRI to provide this information. The results of the trun-

cated audit show strong questions about the appropriate use of more than \$1.2 million in legal expenses; the questionable classification of an additional \$632,438 in legal expenses; and questionable lobbying expenses of more than \$13,591 over a two year period. State contracts do not allow funds to be used for lobbying.

The Department of Mental Retardation (DMR) is responsible for clients at JRC who are older than 21. Those who might be younger are monitored by the Department of Education (DOE) and the Local Educational Authority (LEA) for the community in which the student resides.

Videotapes are not evidence of effectiveness, they are vehicles of persuasion

Although JRC-supplied videotapes and anecdotes abound, firm hard data, presented in a fashion that would allow other researchers to duplicate the techniques and report on their findings, do not exist. Videotapes are not evidence of effectiveness, they are vehicles of persuasion. It is the equivalent of the old laetril* lobby proclaiming, that laetril is effective against cancer. Did they have test data? No, but they had great anecdotes—up until the FDA did studies showing it to be worthless.

JRC argues that self-injurious behaviors are so destructive and inexplicable that analyzing the behavior is unlikely to illuminate its cause. They acknowledge that punishments must be continued forever, but, they argue, the few young people who engage in these behaviors are so fundamentally different than other people that no other course is available. They offer no evidence of this fundamental difference. One cannot analyze why these young people are doing what they are doing, one can only respond.

* In the 1970s there emerged a folk drug, laetril, which was derived from a substance in peach pits. Supporters insisted it cured cancer. Laetril became the darling of the school of thought that insists doctors and the pharmaceutical lobby want to keep truly effective therapies from patients. They wanted the FDA to approve it for general use without any of the usual testing. The lobby for this drug became so vociferous that the FDA was forced to test it. Testing found that laetril had no effect what-so-ever. The support for it vanished overnight.

A Discussion of Aversives: Why They Don't Succeed and What Does

By: Polyxane S. Cobb

Coalition for the Legal Rights of People with Disabilities

A toddler reaches up toward the handle of the pot on the stove where the soup has just come to a boil. His mother slaps the hand away, turns the handle inward, and then goes to comfort the crying child. What she has just done is employ an aversive technique. No one would fault her intervention, nor the seriousness of the consequence if she had not intervened. But everyone would also acknowledge that the intervention would not have been necessary had the handle of the pot not been within reach of the toddler.

Aversives, quite simply, are negative consequences for undesired behaviors. They can be mild. “if you get your clothes dirty you don’t get ice cream for dessert,” or severe, “clean your room or you’re grounded for a month!” They can also be invasive such as spanks or slaps.

When employed as part of a behavioral program for children and adults with developmental disabilities, the matter is rightfully of public interest. The principle question always is: are aversives effective? And what do we mean by effective anyway?

States throughout the US have banned aversives. A number of states such as California, Connecticut, Rhode Island and New York have actually passed legislation banning the use of aversive techniques. In Massachusetts we have failed to ban aversives. One school has been identified with the use of these methods—Judge Rotenberg Center (JRC) and it has successfully fought legislation to terminate its use.

Aversive Therapy promises that dangerous, anti-social, self-injurious behaviors will be eliminated through the use of punishments. It works on the assumption that when people are punished for bad behavior, they will stop it and, instead, do whatever it is the people in control consider desirable. But is there any evidence at all that it works?

The indications that any behavioral therapy is successful are fairly straightforward:

- 1: The undesirable targeted behaviors are eliminated,
- 2: The therapy can be withdrawn slowly until it ceases altogether and the undesirable behaviors remain eliminated, and
- 3: Desirable behaviors are acquired as part of the process

Although the indications that a therapy is successful are straightforward, the process of developing those techniques and applying them to individuals is far more complex. Every behavior must be analyzed. The environment and its components must be scrutinized. The general health and well being of the student must be known and appreciated. Once all that is done, each behavior must be targeted separately so that it is clear to the student what the behavior is that is generating the intervention.

The Judge Rotenberg Center (JRC) has, over the years, employed a variety of techniques it has labeled “therapy.” These procedures include electric shocks from a device strapped to the student and activated by a remote control, food deprivation, as well as spanks, water sprayed in the face or nostrils, forcing the student to eat jalapeño peppers or other odious foods, and denial of ordinary comforts.

To my knowledge, neither the school, nor Matthew Israel, the Director, has ever submitted data, with replicatable methodology, demonstrating the success of any of these therapies—none—to any journal for peer review. In light of the highly invasive nature of many of these procedures, that unwillingness to submit the work to peer review is striking. Since JRC so vehemently proclaims the success of its techniques, this unwillingness to share the information with other schools that might wish to test the “success” of these techniques is also notable.

However, the school’s use of aversives and painful techniques directly contradicts the policies of three national organizations: The Arc, AAMR (American Association on Mental Retardation) and TASH (the organization has existed since 1974; the acronym once stood for The Association of Persons with Severe Handicaps). No one can deny that these organizations represent the largest family and professional groups dedicated to individuals with cognitive disabilities. TASH states as the purpose of its resolution on “positive Behavioral Supports,” is... “to afford the rights of people with disabilities to receive interventions that are respectful, free of pain and produce changes for the individuals.” It... “calls for the cessation of the use of any educational, psychological, or behavioral intervention that exhibits some or all of the following characteristics:

- dehumanization through the use of procedures that are normally unacceptable in community environments for persons who are not labeled with a disability;
- obvious signs of physical pain experienced by the individual;
- physical injury and potential or actual side effects such as tissue damage, physical illness, and/or severe physical or emotional stress.”

The Arc and AAMR in a joint resolution state: “Our constituents are frequently subjected to aversive and deprivation procedures that may cause physical and/or psychological harm and are dehumanizing. Furthermore, aversive procedures result in the loss of dignity and inhibit

full participation in and acceptance by society.” Thus, the organizations call for behavioral interventions or supports that are . . . ”individually designed, positive, help them learn new skills, provide alternatives to challenging behaviors, offer opportunities for choice and social integration, and allow for environmental modifications.” Aversive therapy is still possible in Massachusetts, despite the overwhelming opposition of these organization.

Murray Sidman, often called the father of modern behavioral analysis has researched just this question. He writes:

Many retarded and autistic children are ordinarily ignored because they are considered to be emotional and intellectual vegetables, unable to appreciate or adapt to their environment. But they sometimes discover that if they damage themselves, hitting, scratching, clawing, lacerating themselves and drawing blood, they bring the whole community down on them; they make themselves the center of attention. These children have been taught, albeit unknowingly by their teachers, to administer pain to themselves as the only way to gain attention. The proof comes when we then provide the same attention for constructive acts; the self-abuse ceases.

The effects of prolonged punishments as a behavioral tool are pronounced. First, punished people become acclimated to punishments. The procedures thus begin to lose effectiveness. The severity of the punishment must then be increased in an ever-increasing spiral. Proponents of aversives such as JRC argue that self-injurious behaviors are so destructive and inexplicable that analyzing the behavior is unlikely to illuminate its cause. Proponents acknowledge that punishments must be continued indefinitely, but they argue, the few young people who engage in these behaviors are fundamentally different than other people. One cannot analyze why they are doing what they are doing, one can only respond.

A second side effect of prolonged punishments is that the student begins to focus on nothing except his stress. He cannot acquire new and useful skills because he is always in a state of fear and apprehension.

A third side effect is that instead of viewing teachers and staff as helpers, they are transformed into negative reinforcers. An approach by the staffer, no matter how benevolent that person’s intentions at the moment, is viewed by the student as a threat and the action as the onset of a cycle of punishment. The very people who should be seen as helpful are, instead, seen as hurtful.

Eventually a state of behavioral depression overtakes the student. He becomes lethargic, anxious, and is often described as zombie-like. An important sense of freedom and personal

security has been driven out of his world by the unrelenting fear of punishment.

This is the bleak, unrelenting future for students treated with such aversive procedures. Since their undesired behaviors are only suppressed, they cannot graduate to less intrusive programs where the suppressed behaviors will re-surface absent the punishments. So organizations employing aversives proclaim a stasis effect: a low level of punishments keeps these students controlled, it maintains, the way insulin controls diabetes.

Students in other programs which do not use aversives and with successes that include progressing to less restrictive environments are regarded by organizations such as JRC as less “involved” than their students. By applying circular reasoning, proponents of aversives claim that: if a student can live outside of the initial program he was not as challenged in the first place. The proof, therefore, that aversives “work” is that JRC students can never leave the program!

So What Does Work?

Severe behaviors always have a rational, if sometimes complicated root. As Sidman pointed out, the young person might simply be trying to get attention but doesn't have a constructive way to do it. He may be in pain or other distress and not have the communicative powers to describe his predicament. He may be trying to do something else entirely and not have the physical refinement to achieve his goal. Whatever the reason, the destructive behaviors focus the attention of caregivers with a power few other actions hold.

The non-aversive techniques to resolve these negative behaviors and replace them with constructive behaviors are varied, but all contain many of the same elements. Techniques such as Gentle Teaching (see www.inala.org.au/behaviour/strategies.htm), the ABC method and others all promote:

- a careful analysis of the targeted behaviors,
- systematic interventions that include ignoring the behavior (but not the person),
- activities that redirect the attention of the person, providing alternative behaviors, and, most critically, numerous and generous rewards for exhibiting desired behaviors.

The rewards are the critical element simply because we all are more willing to engage in behaviors if we are rewarded for them. The most important reward is approval—not candy, not money, not a trip to the mall—approval. And when instituting a behavioral program, the generous use of approval for all desired or acceptable behaviors creates a positive atmosphere that stimulates the young person to engage in ever more frequent positive behaviors.

If Positive techniques are so great, how come they don't work on JRC students?

Positive techniques do work on JRC students and elsewhere.. The few who have been moved to other facilities where positive approaches are the norm have flourished. Some have found jobs and become taxpayers. Others have moved into community residences and day programs where positives only approaches are used. None have been transferred back to a program that uses aversives. Indeed, schools like JRC maintain that they do use positive techniques and their students still engage in self-destructive and aggressive acts. In the example of JRC, it's true, they offer rewards in the form of chips that students can cash in for time in the Big Reward Store and rewards delivered to the students' workstations, but the backbone of the program is the use of aversives. Positive approaches, however, must be comprehensive. The initial approach, the constant motivator, and the underlying theme of the program must be positive.

States throughout the US have banned aversives. California, Connecticut, Florida, North & South Dakota, Pennsylvania, Arizona, Rhode Island, New York*, New Jersey, Nevada, and Colorado have all passed legislation banning the use of aversive techniques. Some are more comprehensive than others, but all have shown a strong inclination to promote the dignity and personal autonomy of people with developmental disabilities. It is a step Massachusetts has yet to take.

* New York has regulations that limit the use of aversives and there is a bill working its way through the legislature, but the law has yet to be passed.

A Chronology of the Death of a Teenage Girl at JRC

On January 6, 1995, the Judge Rotenberg Center (JRC) was notified that abuse had been substantiated in its handling of the last days of Linda Cornelison, a student at the program. JRC/BRI was cited additionally for violating numerous DMR standards and regulations at the time of the young woman's death.

Linda Cornelison was 18 years old when she died of a perforated ulcer early in the morning of December 19th 1990. She weighed 90 pounds at autopsy and was 5' 5" tall. Linda was non-verbal—her communication consisted of a few rudimentary signs and gestures. Diagnosed as having a variety of disorders over the years, she had severe retardation, (an I.Q. of 30), was non-verbal, and had epilepsy.

Tuesday December 11, 1990

Linda enjoyed eating, but during the day of Tuesday, December 11th it appears she was not eating all or part of her meals. The records of these days are unreliable, some are missing. Whether she was, indeed, not eating and thus showing the first signs of the perforated ulcer that would eventually kill her a week later, or was not being fed as a punishment for her behaviors is not known from the data provided to investigators by BRI/JRC.

Evening — Saturday, December 15, 1990

Linda refused her dinner on Saturday evening according to two staffers. This was unusual—Linda always had a good appetite, liked to eat. Indeed, she was always wanting to eat. Linda had been put on a contingent food program: if she met the expectations of the staff she was fed. Her caloric intake had been held at approximately 300 calories/day for a number of days.

All Day — Sunday, December 16, 1990

By the morning of the 16th Linda was showing definite signs of illness. The staff member that first made note of her unusual behaviors was well acquainted with her, having been working with her for nearly two years, five days a week. Linda was refusing snacks during the hour and a half bus ride from the residence in Attleboro to the school in Providence in Rhode Island and was being fidgety. She was also making unusual sounds.

These signs apparently continued during the day—and equally apparently this particular staffer found it notable enough not to deem these negative behaviors and punish Linda for them. The number of punishments administered on this day was only three—down from 9 the day before and 20 two days earlier. It is unclear whether the day staffer(s) advised those on the evening shifts about Linda’s unusual behaviors, but those working overnight did observe these signs. They did not, however, notify the nurse or other medical staff. There is also no indication that the evening staff notified the next day’s staff of their observations.

Morning — Monday, December 17, 1990

Linda awoke in clear distress. She didn’t eat breakfast and was fidgety. The staffer recalls notifying the nurse of Linda’s condition, but no one in the medical office recalls being notified and there is no written record of it.

She was driven to school where, during the day her condition worsened. We know now that Linda had multiple ulcers in her stomach (medical report) and that there was a perforation that was allowing the contents of the stomach to invade the abdominal cavity. Infection and an acute inflammation of the peritoneal lining was occurring during this time. She was in pain and, since she was non-verbal, was totally unable to say so.

Afternoon — Monday, December 17, 1990

The reaction of the staff to Linda’s distressed behaviors was notable. The punishments increased. She was forced to breath in ammonia vapors six times during the day, had deep muscle squeezes 18 times, and was spanked four times. The ammonia was particularly difficult to administer. Staff reported, “it was a fight to give Linda ammonia. She’d be in a panic and try to get away from you. It used to break my heart, she’d panic and grab me.” On this day, with her stomach acid leaking into her abdomen, the punishment must have been particularly agonizing.

During the hour and a half on the bus ride home, she again refused snacks. Later she refused her dinner. While the stream of punishments continued, staff also noted,

“...she seemed fairly sick.....she looked white.” “...she looked pale and tired...”

Night— Monday, December 17, 1990

Over the course of the night she repeatedly got out of bed and walked around, only to go back to bed. Soon she would be up again. Linda ordinarily slept at night, perhaps using the bathroom once, so these behaviors were unusual and notable. She was, one of the staff said, “very lost, looking all around her like she didn’t know where she was.”

Another reported that , “she kept going to the bathroom, she had attempts to vomit...”, while yet another said, “...her eyes were glassy and Linda never slept...”She “had been awake all night sticking fingers in her throat.”

The staff didn't, apparently, call the nurses to check her for illness. Linda's night was a prolonged series of unsuccessful attempts to treat herself—with staff, apparently doing little but note her behaviors—and punish her for them.

During this night as her stomach pain became more and more agonizing and she tried to vomit to relieve the burning, Linda was spanked eight times, had a number of deep muscle squeezes, was forced to inhale ammonia, and had what are called taste aversives, vinegar mix, jalapeno pepper, or hot sauce, administered several times. There is no indication that the events of this evening and night were reported to the next day staff.

Morning — Tuesday, December 18, 1990

The last day of her life dawned in pain for Linda. “She was trying to tell us something.” said one staffer. “I honestly thought she had a pain in her stomach.” She, “had inappropriate Urine] and was very non-compliant.” “...she had inappropriate motion and was touching others...” “she was pulling the clothes at her stomach. She was touching her stomach like she had menstrual cramps...” “...she was bringing her feet up to her stomach, her knees to her chest, holding her stomach...” These symptoms were noted but no one, apparently, thought them serious enough to take Linda to a physician or even to call the nurse to examine her.

Indeed, in spite of the clear distress she was in, staff put her on the bus to go to school. For the next hour and a half, “...she was limp hanging onto me on the bus. She got out of her seat and put her head on my shoulder...” “she had 1-1 (one staffer assigned only to Linda) because she was sick. She does not [usually] require 1-1 on the bus...”

When they arrived in Providence, Linda had to be carried into the school. She was put on a cot at the back of the room. From 9:00 a.m. until 3:00 p.m. no aversives were applied. Everyone knew she was sick by then. The nurses saw her, several staffers commented on it. She continued to refuse to eat. Although she was checked several times, by several people, there is, remarkably, no documentation of a physical exam including Linda's abdomen nor did anyone think to suggest seeing a physician even after she had missed two meals and was unable to stand.

Although the nursing staff has the authority to remove aversives when a client is ill, they did not do so in Linda's case. Indeed, the nurse had never, in the 40 years since graduating from nursing school ever taken a formal physical assessment course for nurses. It is not clear that the nurse understood how serious Linda's condition was.

3:00 p.m. to 8:00 p.m. — Tuesday, December 18, 1990

From 3:00 to 5:00 Linda remained on the cot in the back of the classroom. No nurse checked her condition in that time. For that matter, neither the nursing staff nor the first day shift staff communicated with the second shift staff about Linda's illness, nor did nursing staff "leave instructions about whether or when to call them or other medical personnel." For two days Linda's illness raged but at every shift change the new shift was not informed by the departing shift that she was ill. No one knew, therefore, how long she had been ill or how the symptoms had progressed in intensity over the two days.

This tragic omission led to an appalling misunderstanding on the part of both supervisory and direct care staff. Linda's tortured writhings were interpreted as behaviors, not symptoms of illness, and she was punished for them—severely. Between 3:52 and 8:00—4 hours and eight minutes—56 physical aversives were administered to her: about 1 every 4-1/2 minutes. She was spanked 13 times with a spatula, had her fingers pinched 29 times, her muscles squeezed 14 times, and had administered what are called odor aversives (ammonia, for example) five times. Indeed, as the afternoon and evening progressed, staff requested—and received—permission to increase the number of aversives that could be applied to Linda. At autopsy bruises were noted inside both upper arms, the frequent site of muscle squeezes.

Between 7:00 and 8:00—the last hour before staff decided to call for medical assistance, she was spanked five times, finger pinched two times, and administered ammonia.

From 6:30 to 8:00 no one documented Linda's condition except to note the extraordinary number of aversives that had been administered.

At 8:00 a staff supervisor was called to come upstairs to see Linda (she had been downstairs in the kitchen cooking and had not, up to that point, been involved with Linda all evening) because Linda was, "on the floor and won't get up [and] that something was wrong with her."

She found Linda sprawled on the bathroom floor. Her eyes were glassy and she was extremely pale. She was described as semi-responsive. Another staffer, a man, stated that her skin was bluish. Two or three people carried her from the bathroom to the bedroom.

The supervisor immediately called the nurse to say that Linda was "very ill" and should go immediately to the hospital. The nurse wasn't so sure and asked the supervisor to wait until a person described as "medication certified administrator" arrived to give clients their medications. Thus another half hour went by until this person arrived.

At 8:39 Rescue was called. The medication administrator checked Linda before the paramedics arrived and noted that "her extremities were blue/purple, she had labored breathing,

her eyes were glassy, and felt a pulse rate of 110.” She could not, in fact, detect the pulse in either arm or Linda’s foot, and had to take the pulse rate from the carotid artery.

8:45 p.m. December 18th to 1:45 a.m. December 19th, 1990

Linda was wheeled out of BRI’s Frenier House at 8:55 p.m. seven years, two months, and 88,719 aersives after she first arrived in October 1984. She died on an operating table at 1:45 a.m. of a perforated ulcer. Much of her abdominal cavity was gangrenous. She was 19 years old.

Success Without Pain Case Studies

Introduction

What characterizes the stories that follow is the progression from restrictions imposed on these young people to their increasing independence. The process is achieved in a variety of ways. Some programs adhere to specific methodologies that have been refined and researched over the years, others use a variety of techniques with a set of criteria for each individual in their program—essentially individualized programs that mesh with a larger, over-all philosophy.

Some of the young people came from severely restricted settings where their every move was monitored, their every action judged, and their every moment scheduled. Many were never given the opportunity to make any decisions at all for themselves, but were, rather, viewed as being persistently and permanently unable to develop the capacity to make decisions. Their success at those programs was determined by the extent to which which they obeyed and met the expectations of the staff. Their failures were punished.

None of these young people presented simple problems. All have complex, interwoven difficulties that restrict the ways they can acquire information and process it. The challenge for the programs they attend has been to discover the avenues of thought within these young people and assist them in discovering ways within themselves of expressing those thoughts, hopes, desires, and wishes. That their successes have been opulent is not unexpected. It is the result of taking the time—long, often tedious hours, days, weeks, and months—to discover just what the maladaptive behaviors these young people exhibit really mean and to provide them with alternative, positive ways of behaving. In the end, they provide the opportunity to turn aside a life without hope and help these young people achieve fulfillment and promise.

These stories are all true. They are from the programs here in Massachusetts. Some are brief outlines, others more detailed. All are examples of what can happen with caring and in having belief in the capacity of these young people to be just like everyone else.

M.—

M.— is young male diagnosed with autism, schizophrenia and severe mental retardation. Prior to his transition to our residence, M.— resided at the Behavior Research Institute (BRI) in Rhode Island for approximately 15 years. The long standing behavioral issues for M.— included: severe aggression (he had broken the noses of several staff persons); self-injury (biting self); and tantrums (screaming, jumping, and unintelligible talking). While at BRI he was treated with numerous painful aversive consequences and contingent meals for the exhibition of those dangerous behaviors.

Several years ago M.— moved into our South Weymouth home and at the same time attended our day program in Hingham. Our approach to was to increase his communication and reduce his aggressive and self-injurious behaviors by employing functional communication training (fct). Prior to his move, M.— was not encouraged to make independent decisions. With fct, M.— learned how to make decisions from the choices which were presented. His choice-making behavior was reinforced each time staff honored his selection. In less than a year M.— was able to make the decisions regarding his daily activities.

The data on his aggression, self-injury, and tantrum behaviors decreased and remain (today) at a low frequency. Conversely, the frequency of his spontaneous communication rose dramatically. In addition M.— now enjoyed the opportunity to live in a home where meals were served family-style, his rights to privacy were respected (as he now asked for privacy in his room), and he was free from painful aversive consequences.

G.—

G.— self-injurious behavior had become so excessive that people were starting to worry about his safety. Because of autism and a behavioral disability, G.— would hit himself up to 1,000 times a day, inflicting countless scratches and bruises. During one particularly severe episode, he even permanent blinded himself.

“I used to cry after watching my son,” said G.—’s mother, a resident of East Taunton. “I couldn’t stand to see him harm himself like that.”

When G.— turned twenty, his mother felt that he would be better off if he moved into a group home for persons with behavioral disabilities and attended a suitable day program. After moving into Fencourt Street Residence, a group home run by South Shore Mental Health, G.— began attending Vinfen’s Day Development and Transition Center (DDTC) in Brighton. Even with the change, G.— still continued to punish himself. Just when prospects for a better

life looked bleakest, G.— suddenly made a remarkable turnaround.

DDTC staff members speculate that functional communication training helped G.— learn that he could obtain those things he needed through adaptive communication rather than maladaptive behavior. Because G.— is also blind, staff worked intensively with him to use tactile discrimination (i.e. shapes and textures) to identify his needs and wants.

Steve , a Clinical Behavioral Coordinator at DDTC–Hingham, feels that G.—’s increasing command of language is helping him to convey his feelings better. “I think he used to be frustrated because no one could understand his needs,” he said. “Now he’s more effective in getting his point across.”

The change of scenery also worked to G.—’s benefit. “He’s much more relaxed these days,” added his mother. “Now that he goes to DDTC’s branch program in Hingham, he doesn’t have to travel as far. That’s less of a drain on him and makes him more at ease.”

The move to DDTC–Hingham coincided with a change in the focus of his Individual Service Plan (ISP). His ISP Team believed that G.— needed more assistance and training in functional life skills, with the hope that he would become more independent.

Currently G.— moves about without assistance. Using his hands to feel cut out shapes and textures which are adhered to doors, G.— is able to distinguish between the kitchen and the bathroom. He has also learned how to wash his hands and how to eat by himself.

G.— has also made a lot of progress behaviorally. “He had averaged almost zero periods of self-injurious behavior a month for the past two years,” explained Steve, “and is becoming more independent.”

Needless to say all of this progress has made G.— a much happier person. “I just can’t believe the change in him,” said G.—’s mother. “He laughs and smiles more and looks forward to taking part in outings with other consumers. It’s phenomenal how far he has come in two years.”

R.—

R.— arrived at Delta Project’s respite facility in Mansfield in 1985 from Behavior Research Institute (BRI). R.— had a long history of running away. During these runs, he would leave the state, steal cars and check into shelters and hospitals.

Delta provided R.— with 1:1 supervision at all times. He would earn points for appropriate behaviors and be fined points for running away, threatening to harm himself, and fabricating stories. R.— would earn preferred activities or items once he earned a designated amount of points. This could occur on a weekly or monthly basis depending on what R.—

chose to earn.

R.—'s counselor feels R.— runs away from himself and his issues of sexuality. Having a counselor to talk with on a weekly basis has assisted in alleviating some of his anxiety.

With staff support, R.—was able to obtain a job in the community working full time. He was assigned a job coach who taught him the responsibilities of the job. In time, R.— feelings of pride and self-respect grew and the running behavior decreased. Being able to have a say in what happens, when they are going to happen, and given a chance to take control of his own life were all critical factors in R.—'s success.

R.—'s success has afforded him the opportunity to move into a less restrictive setting where staff were not present around the clock. He sits on the Human Rights Committee of Delta Projects as a participating member, goes for independent walks and train rides into Boston and out where he chooses to go.

D.—

D.— came to live at Cooperative for Human Services (CHS) in 1987, moving from a 766 residential school after turning 22. He had previously spent most of his life at W.E. Fernald State School. This young man exhibited severe self-injurious behavior, including face punching and slapping, chin punching, head-banging, hitting his body, repeatedly hitting his hip with his arm, and repeatedly kicking his shins. His face slapping and head-banging had resulted in a detached right retina, blinding his eye and his left retina remains vulnerable. Initial frequencies of self-injurious behaviors were over 2,000/day.

When D.— arrived, he wore arm splints from his wrist to above his elbow, as well as a padded hockey helmet. These devices were initially removed only to eat, shower, and sleep, and at regular intervals for exercise. It took three people to safely shower him and a styrofoam liner had to be installed in the shower stall for safety.

It took 14 months to fade the splints, initially modifying their length, then replacing them with weightlifter's gloves and wristbands. The helmet was gradually faded as well. During this time, CHS staff worked hard at getting to know D.—, and learning what he liked and disliked. Initially, demands were lowered and his activities were modified to reflect his own preferences. At his day program, he was moved from benchwork to assisting with janitorial duties, since he liked to move around.

D.— is non-verbal, so priority was given to understand the communicative significance of his self-injurious behavior. For example, he would often walk into the kitchen, face the refrig-

erator, and begin hitting himself. He was taught that he could open the refrigerator and choose something to eat. He would also stand in front of the front door and bang his head against the wall or door frame. Frequent walks were built into his scheduled activities.

Medical issues were also examined to determine any relationship to his self-injurious behavior. At one point, rubbing his chin on his shoulder caused severe abrasions to both. It was determined that D.— in fact had two impacted wisdom teeth; after their removal the behavior stopped. Repeated stomach punches were related to chronic constipation. His medication is carefully monitored and frequently reviewed.

D.— currently does not wear a helmet or any other protective device. The helmet is still available for use when certain criteria are met (e.g., any hit to the left side of his face); the frequency of use is four to five times a year. He has not had a serious crisis since 1991.

Although D.— does not talk, it is clear that he understands a great deal, so he is included in conversation now in ways that are new. Someone is focused on him at all times; this does not mean he is shadowed at every moment. Rather, as he does things in the house or in the community, there is one staff whose job is to attend to him, in a way that is comfortable for him.

We know that D.— requires an environment that is structured to permit him to determine for himself what is happening. He is beginning to make simple choices on his own—what to drink, for example. He has a lack of judgement about things, and we are working on setting up opportunities for him to practice making safe, simple, choices, so that he can move on to making more important, complicated choices. D.— seems to enjoy different things from his roommates; he's pleased, for example, to wander around the house making music with objects or singing. He has perfect pitch and readily imitates music or a background melody. He sometimes chants, and will sing "duets" with staff who know how to make music. His interest in music is brief, however; he is not interested in playing a musical instrument, or in singing along with staff for very long.

D.— has begun to initiate activity on his own, and seems to recognize when a situation presents an opportunity. For example, recently when staff were involved in helping another client deal with an outburst, he went to the refrigerator, removed an item that he is not supposed to get on his own, and came in to staff to show them that he had it with a smile on his face. D.— also now spends times at home with his mother, which is something he never used to be able to do.