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ABUSE UNCOVERED IN DEATH AT BRI
Victimization of 19-year old Linda Cornelison called
"inhumane beyond all reason"

This is the full text of an article describing a recent investigation into a death of a young woman at BRI - it appeared in AUTCOM's newsletter, *The Communicator* ((1995), vol. 6, no. 1.)
This report is excerpted from bulletins of the Coalition for the Legal Rights of People with Disabilities.

The Disabled Person's Protection Commission (DPPC) and the Massachusetts Department of Mental Retardation (DMR) released the report of an extensive investigation into the death of a 19-year old woman who died in 1990 at the Judge Rotenberg Center (JRC, Formerly the Behavior Research Institute, or BRI). The investigation, which included interviews of 72 witnesses, review of hundreds of documents, and reports by four experts, concluded that JRC/BRI direct care staff, nursing staff, and administration, as well as several specific staff members, took actions that were "egregious" and "inhumane beyond all reason" and constituted not only violations of legal standards but violations of "universal standards of human decency." Abuse and violations of DMR regulations were also found in the woman's treatment by JRC/BRI prior to her death.

The Judge Rotenberg Center has been the source of controversy for years because of its heavy use of "aversives," which involve physically punishing people with mental retardation or autism to influence their behavior.

The woman, who was mentally retarded and could not speak, began showing signs and symptoms of illness on December 15 and 16,1990: she refused her food (she had always had a hearty appetite), she was restless and fidgety and made unusual noises. By December 17, she was pale, disoriented, had "glassy eyes," and kept attempting unsuccessfully to vomit. During this time, because staff mistook her attempts to communicate her pain and discomfort for "target behaviors," she was punished repeatedly -- forced to smell ammonia, spanked, pinched, and forced to eat "taste aversives" -- either a vinegar mix, or jalapeno peppers or hot sauce.

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On the morning of December 18, after a 1-1/2 hour bus ride, she got off the bus and wouldn't move. She sat in a puddle, and had to be carried into school.

>From 4:00 p.m. to 8:00 p.m., even though staff knew she was "not herself," her punishments escalated dramatically. By 7:00 p.m. she had received 8 spankings, 27 finger pinches, 14 muscle squeezes and had been forced to inhale ammonia at least five times and given several taste aversives, even though she was "obviously ill." In fact, she was receiving so many aversives that staff requested and were granted permission to increase her aversives from 40 per day to 95 per day. She received a total of 61 aversives on the day that she died. The total number of aversives on December 17 and 18 was greater than the number she had received in the entire month of December up to that point. She had always disliked the aversives, and was terrified of the ammonia, but protests or attempts to avoid them simply led to more punishment.

Nursing staff was not notified until the morning of December 18 about her condition. Even though the nursing staff knew she was ill, no one kept her out of school, stopped her punishment program, or made any effort to determine whether the behaviors leading to punishment were attempts to communicate her rising pain. The first nursing shift, although notified she was ill, did notpass that information along to the second shift. From 3:00 p.m. until 8:00 p.m. on December 18, no one with any health care training was monitoring her condition.

At 8:00 p.m. on December 18, she was lying on the floor of the bathroom and unable to get up, pale with a bluish tinge to her skin. Although a registered nurse was notified, she refused to call an ambulance until a medical technician arrived and confirmed the need for it half an hour later. By the time the 19-year old woman reached the hospital, her blood pressure was zero and she was in shock. She was not operated on until 12:45 a.m. She died on the operating table at 1:35 a.m. on December 19. The Medical Board of Registration and Department of Health are investigating the behavior of the hospital in delaying surgery for three hours...The autopsy revealed that her stomach had been perforated, (and) that she had extensive ulcers. The cause of the perforation remains unknown.... Although JRC/BRI retained an independent pathologist and conducted their own internal investigation, they refused, despite repeated requests, to make this information available to DPPC or DMR. They refused to give investigators the incident note made about the events of 12/18/90 by a registered nurse, or the nursing notes for this period. Six months of nursing notes were reported missing by JRC/BRI for this period.

Because the woman's death was gastroenterological in nature and related to ulcers, DPPC and DMR investigators and their experts also investigated her treatment through a "specialized food plan." On the specialized food plan, she had to earn her daily meals by not engaging in certain behaviors and/or working on a computer. Ironically, staff confirmed that although her meals depended on her getting right answers on a computer, she neither understood the relationship between getting fed and getting the right answer on the computer, nor how to get the right answer on the computer. "If she didn't earn her food, it was thrown out. She got real thin, she was skinny," said one staff member. Staff also said that she was "always wanting to eat."

The program allowed the 19-year old to be limited to as few as 300 calories a day, 20% of her minimum calorie intake for the day. A dietary expert consulted by the investigator stated that it was impossible to maintain the woman's health on 300 calories a day, and that she needed at least 1737 calories a day to maintain her lowest acceptable weight, 108 pounds. Although JRC/BRI was under a court order to ensure that her weight did not slip below 90% of ideal body weight, the autopsy report showed that the woman, who had weighed 125 pounds when she was put on the food program less than a year before her death, weighed 90 pounds. In less than a year, she had lost 35 pounds, 28% of her body weight.

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In addition, although DMR regulations permit the use of intrusive and severe aversives such as spanking and ammonia for "seriously dangerous behaviors," the woman was punished when she displayed the following behaviors: "Drooling, spitting, nagging, stopping work, refusing, silly laughing. She was deprived of food for merely having the wrong answer on the computer."

In related BRI news, in January 20, 1995, the Massachusetts Department of Mental Retardation issued its report and Decision on Certification to Use Level III Interventions to JRC/BRI. The Department's regulations related to behavior modification and four out of twelve conditions of certification. Based on their findings, the Department ordered JRC/BRI to terminate the use of Level III interventions (which include the use of all painful aversives such as shock, forced inhalation of ammonia, water squirts, taste aversives, denial of meals) on six residents. The Department granted conditional certification permitting JRC/BRI to continue using Level III aversives on the remaining residents.

The Department found that despite a requirement that Level III -- the most intrusive and painful interventions -- be used only to control "extraordinarily dangerous behaviors that cause serious harm," JRC/BRI was restraining and shocking residents, denying them food and forcing them to smell ammonia inhalants for behaviors such as "nagging," "slouching," "silly laughing," "refusing to get up out of seat," "tearing paper," "staring at objects, "staring at thumb or fingers," or "holding one hand with another while looking at his thumb"...Residents are also shocked for trying to remove the electric shock device attached to them, or for grabbing at staff when they are shocked. One staff member stated that while VI's treatment plan called for her to be punished when she was aggressive, she was in fact only aggressive when she was punished.

In addition, despite requiring that these measures only be used when they are the least restrictive and most appropriate to a resident's needs, the Department found that JRC/BRI used these interventions even when far less intrusive and painful interventions were more effective...When aversives were lowered for the client who died on 12/19/90, her problem behaviors went down....

JRC/BRI repeatedly barred access to the Department for necessary reviews and investigations.

(Excerpted from "Abuse Confirmed in Death at BRI," and "The Department of Mental Retardation Finds Serious Violations of Regulations at JRC/BRI," bulletins of the Coalition for the Legal Rights of People with Disabilities.)

Eric MacLeish, BRI lawyer, stated, "Linda's death was tragic, but it was not the result of negligence. We didn't do anything wrong. We loved her.

Despite the report of the probe into the death of Linda Cornelison, which was delivered to top DMR officials on January 3, and despite the findings of serious violations in the treatment of other clients, on January 20 DMR conditionally recertified JRC/BRI.

JRC/BRI is currently in litigation with DMR, claiming that the Department has acted in bad faith in its attempts to question or curtail the use of aversives. Eric MacLeish, BRI lawyer, stated, "Linda's death was tragic, but it was not the result of negligence. We didn't do anything wrong. We loved her."

BRI administrators were questioned by legislators at a public hearing on February 22 at the Massachusetts State House. BRI Director Matthew Israel, PhD, defended his program by citing the Autism Society of America (ASA) position statement declaring that each family has the right to "select options they feel are most appropriate for their autistic family member" and insisted that aversives constitute effective "therapy." However, he was forced to admit that 5,300 electroshocks in one day did not work for one BRI client. State Rep. James V. DiPaola, a former police sergeant and vice chairman of the Joint Committee on Human Affairs and Elderly Services, self-administered an electroshock from BRI's machine, which caused him to leap out of his seat. "It was torture," he stated. "It was very painful."

Also speaking at the hearings was BRI's attorney Eric MacLeish, who branded Roberta Cornelison's malpractice lawsuit against BRI as "irresponsible."

(reported in The Boston Herald, Feb. 15 and 23, 1995, and by AUTCOM members in attendance)