THE DOCTORS GROUP
1101 BEACON STREET
BROOKLINE, MA 02146

TEL 617-731-6333

DONALD S. STERN, M.D.
Internal Medicine
Gastroenterology

JAMES M. RABB, M.D.
Gastroenterology
Internal Medicine

MARK J. ELLENBOGEN, M.D.
Pulmonary Medicine
Internal Medicine

December 28, 1994

Mr. Richard Cohen
Department of Mental Retardation
160 North Washington Street
Boston, MA 02114

Dear Mr. Cohen:

The following report summarizes my views on the [redacted] case. I have addressed all of the issues that I felt came out of your original questionnaire and our meeting in early June.

The questions I have been asked to discuss are:

1. What disease did [redacted] die of?
2. did aversion therapy administered by BRI contribute to her demise?
3. Might she have survived had more prompt definitive therapy been administered.

4. did the care provided at BRI conform to acceptable medical standards?

1. The time course of her illness was well-documented. According to her mother she was well three days prior to her death. She had never had GI symptoms of any magnitude in the past. Two days prior to her death she began to exhibit unusual behavior suggesting a gastrointestinal illness According to a supposedly competent nurse observer she appeared to have had at least a brief period of relative remission a few hours before the catastrophic turn of events later in the afternoon of the eighteenth of December, 1990. Shortly after that another nurse recognized that [redacted] was severely ill and had her transferred to a local hospital. There she demonstrated peritonitis and shock, was subjected to an appropriate laparotomy where a large gastric perforation was found, and rapidly deteriorated and succumbed as a result of the well-described and understood events following the perforation. The autopsy report documented a large, 8 cm perforation in the distal half of the anterior wall of the stomach with erythema of the remaining mucosa.

On microscopic examination there was acute hemorrhagic ulceration and necrosis at the defect and in distant areas of the stomach foci of the same with submucosal and serosal edema. There was gross and microscopic peritonitis in the rest of the abdomen. There was a "vinegar smell" to the peritoneal contents and brown fluid in the stomach.

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Toxicologic studies of the blood were negative but limited to agents which probably cannot be implicated in ulcer diseasc.

The above observations do not suggest a specific etiology for the patient's illness. On the other hand, ingestion of a substance like lye which causes corrosion on contact is ruled out by the negative gross examination of the mouth and esophagus. Important inadequacies mar the post-mortem examination. There are no observations which might include or rule out any anatomic abnormalities of the stomach. Was there torsion along gastric ligaments? Was there a paraesophageal hiatal hernia? There is no mention of investigation into H. pylori in the microscopic examination. That is the bacterium which is associated with ulcer disease. Even now a pathologist might be able to distinguish on microscopic examination a "stress ulcer" from one associated with H. pylori or an ischemic insult caused by one of the anatomic abnormalities mentioned above. Blood, peritoneal fluid and gastric fluid were not tested for any of the ulcerogenic non-steroidal anti-inflammatory drugs (NSAIDs). The patient has a prescription for Naproxen reported in her record. It is not clear whether or not she had used that medication in the near past.

I recommend that an independent consultant pathologist interview the original pathologist with regard to gross findings, review the microscopic material and retest any available blood or fluid for NSAIDs to attempt to discern an etiology.

I have no comment about the unusual stain on the patient's face.

2. The record in my possession gives no compelling evidence that the attempts to feed her or that any of the agents used in aversive therapy or the therapy itself contributed to her demise.

Despite popular belief the scientific literature has not conclusively connected pepper oils or ammonia with ulcer disease. but there are scattered reports of gastroenteritis.

The concept of "stress" as an etiologic factor outside the intensive care or neurologic unit settings is vague and has numerous definitions and connotations. One cannot definitely show that emotional stress, punishment, or food deprivation per se are ulcerogenic factors for the stomach in human beings.

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That the patient may have had no symptoms of any kind before duodenal or stress ulcer perforation is a well-known clinical observation. Ischemic perforations due to torsion or paraesophageal hernia are usually but not always preceded by symptoms. Thus, her completely asymptomatic state prior to her acute illness does not help define the cause.

3./4. The patient did receive some medical attention prior to her demise, but there were significant lapses and delays which probably played some role in her death. Ms. Donna Cabral's investigative report marked "draft 12/-3414/94/b" and the draft marked "Report/Health/Medical/Death Review, [redacted]" and prior medical records and investigations provided by the Department of Mental Retardation provide the basis for this particular information.

Ms. Cabral's investigative report documents that the school nursing staff despite their suspicion that [redacted] was ill did not forward either their apprehension or a directive for close observation to the personnel at [redacted] residence. It appears that no one with any medical competence observed her from the time of her departure from the BRI until 8:00 PM at which time her acute deterioration was reported by the residential supervisor to [redacted] Inexplicably she delayed the ambulance call until the arrival and corroboration of someone she believed had more expertise or authority. It is my impression that she had been employed to perform such tasks. The rescue service responded promptly and brought [redacted] to the hospital. Despite the patient's presentation with an obvious abdominal catastrophe requiring urgent surgical care, a situation which would make normal operative permission unnecessary, the attending physician delayed the operation for up to three hours to obtain such a permission from a family member. It is unclear whether that family member in fact could be considered close enough to authorize such a surgery. The total delay from the time of her perforation to the performance of the only therapy which could have saved her was four to six hours. [redacted]'s condition as described seems to have demanded a more rapid intervention.

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One can disagree with judgements made by medical and psychological staff in the days and hours prior to 6:00 pm on [redacted]'s last day. In retrospect they appear both unwise and incorrect. On the other hand in the absence of more specific or pronounced symptoms a competent physician might have opted for observation by competent medical staff. An abrupt change in status would have been noted and prompt and appropriate steps taken. The absence in the record of written documentation of communications and observations of the last 24 hours, of institutional policy addressing the case of a medically ill patient, or of specific qualifications of nursing personnel might be overlooked were there any evidence that appropriate actions had been taken. Unfortunately, in this case it appears from available data that no one at the residence was informed of the necessity for observation, that competent staff was not available, that there was a significant delay in recognition of the evidence of a critical situation, and that once the nature of the emergency had been identified definitive surgery was not performed within a reasonable period of time.

Thus, if the evidence as described is confirmed the care provided to [redacted] failed to conform to standards prevalent in the community and may have contributed to her death.

Sincerely,

James M. Rabb, M.D.

JMR/djm

The Commonwealth of [illegible]
Executive Office of Health and Human Services
Department of Mental Retardation
INVESTIGATION DIVISION
COMMUNITY SERVICE CENTER SOUTH
68 N. Main Street
Carver, Massachusetts 02330

Area Code (617)
727-9088

Area Code (508)
866-5000

Area Code (508)
866-5000

Philip Campbell
Commissioner

Richard J. O'Meara
Regional Director

Rod Johnson
Senior Investigator

MEMORANDUM

TO: Daniel A. Connolly, B.R.I.

FROM: Donna Cabral, Investigator/DMR DC/rp

DATE: April 5, 1994

RE: Case File of [redacted]

Thank you for forwarding to me a copy of the new policy B.R.I. has initiated regarding "Copying Documents". As you must be aware, there currently exists an ongoing account regarding this case file. Specific to the new policy, "requesting copies of documents should be specified in writing," please see the following. Also, please be advised, copies of the documentations requested below have been previously requested verbally, either with [redacted] or [redacted]..

I RESPECTFULLY REQUEST COPIES OF THE FOLLOWING:

1. Clinical Log (also known as) Notification/Court Monitor Book fror 1/90 to 12/90

2. A report of [redacted] to B.R.I. dated 12/18/90 (not th therapy note)

Memo to [redacted]
Re:

3. B.R.I.'s:

   A. Behavior Modification Policies

   B. In-Service Training/Orientation

   C. Summary of 1986 Follow Up Study

   D. Overview of B.R.I. Program

   E. Reduction of Psychotropic Medication

   F. Policy and Procedure Regarding Storage of Medication, Controlled and Non-Controlled Substance

   G. Policy and Procedure Regarding Storage of any other Substance, including the Date the Policy was Implemented, the Identification of the Substance

4. CLEAR COPIES OF:

   A. Caloric Intake Sheet from 12/1 - 12/18/90

   B. Daily Tally (aka) Recording Sheet Dated 12/16, 17, & 18/90

5. Yearly Tally Sheets from Admission to 1990

6. Monthly Tally Sheets from Admission to 1990

DC/rp

cc: File

[redacted]

REASON FOR REVIEW

[redacted] was a student at Behavioral Research Institute, Inc. (BRI), Providence, Rhode Island, from October 2, 1984 until her death on December 19, 1990. Due to concerns regarding the circumstances leading to [redacted]'s demise, a review of the case was requested by Richard Cohen, Esq., Director of Investigations, Massachusetts Department of Mental Retardation (DMR) by this consultant and Ms Donna Cabral, Investigator, DMR.

SOURCES OF INFORMATION

Information was obtained from documents provided by BRI, current and former BRI staff, and review of reports done by consultants Angela Duarte, Ph.D., Deborah Dessaint, MS, RD, LDN, James Rabb, M.D.

PAST HISTORY

[redacted] was born on February 23, 1971 in New Bedford, Massachusetts. Birth weight was seven pounds and twelve ounces.

vaginal delivery was performed under spinal anesthesia and forceps were used. Apgar score was seven. Baby was cared for in the regular nursery and went home at five to six days. Mother "..was concerned from the very beginning/[redacted] seemed alert and smart and attentive but unresponsive... At around 2 years, Children's Hospital (Boston) diagnosed [redacted] as developmentally delayed".

Prior to admission to BRI, care was sought at various agencies. From age seven to thirteen (1978-1984), [redacted] resided at Bradley Hospital, East Providence, Rhode Island, Autistic Unit.

Relevant childhood medical history includes seizure disorder, heart murmur, constipation, bed wetting, and "hands and feet always feel cold and have turned blue when they were at her side in a warm room". Allergies to Haldol and phenobarbital were noted.

Relevant behavioral history includes aggressive behavior, headbanging, and hyperactivity.

BEHAVIORAL RESEARCH INSTITUTE

[redacted] was admitted to BRI on October 2, 1984 where diagnoses of autism and mental retardation were made.

Available annual medical and periodic nutritional evaluations were

reviewed from the years 1987 to 1990. In February 1987, Dilantin was increased to 100 mgm by mouth BID (2x/day) due to a low serum level of 4.9. In December 1987 a physical exam was notable for a [possibly] "minimal type one murmur..." [redacted] was noted to be "doing quite well" and routine care was advised. Height was recorded at 62" and weight approximately 114 pounds. A December 1988 evaluation noted seizures in good control, diagnosis of a sensori-neural hearing loss, functional heart murmur, acne, and dysmenorrhea (painful periods). Naprosyn 250 mgm po 3x/day, prn, was utilized for menstrual discomfort. T-stat was prescribed for acne. Height was 63", weight 112 pounds. September 1989 nutrition evaluation noted: " Calorie level was changed (6/17) from 2500 calories to 2000 calories due to weight gain". A December 1989 medical evaluation noted previous treatment with penicillin for "strep throat" and a lipoma [benign fatty tumor] which spontaneously resolved. Height was 64", weight 125 pounds. [redacted] was described as "well-developed, well-nourished" and noted to be doing well. There was no mention of the need for any dietary modifications (i.e., for weight loss) or the use of a specialized diet. However, the same physician, [redacted] M.D., evaluated [redacted] on 12/27/89 and stated: "[redacted] was seen today as part of the food program. She appears to be doing very well". Laboratory parameters obtained at the above evaluations showed normal complete blood counts and urinalyses.

A nutritional consultation January 1990, noted that "calorie level

was changed from 2000 calories to 1800 calories (8/4), then to 1500 calories (11/8) to help promote weight loss". [redacted] was noted to "be on the specialized food program at this time.... Weight 1/28 was 120 pounds.... Gradual desired increase in weight noted.... Red line 108#.... Will continue to monitor labs, weight and adjust calorie level as needed." [redacted], R.D.). In the document "Permission Packet:... printed 8/24/90 and signed by [redacted] on 9/3/90 it is stated: "BRI's medical staff will establish a desired targeted weight for each student, appropriate for his/her height, weight, age, and program, and will make its best efforts to keep the student's average weight at this level... Students are weighed daily and parents are free to request the weight charts at any time".

In a document filed at Bristol Superior Court, Docket No. 86P1161, and signed by Roderick MacLeish, Jr., on behalf of BRI, an amendment to the treatment plan for [redacted] was requested. The addition of the Specialized Food Program was felt to have "a substantial likelihood of decreasing her non-compliance during a fire drill or other emergency".

In the document "Permission Packet" dated 8/24/90 and signed by [redacted] on 9/3/90, Specialized Food is described: "If special treatment considerations require it, the provision of staple food make-up will not be made, with the approval of a consulting physician, provided, however, that the individual will

always receive at least 20% of his/her caloric target which is set by the nutritionist.. BRI will provide all necessary medical safeguards that the health and well-being of the individual is not jeopardized".

From available documents dated in the month of December 1990, maximum caloric intake was 1550 [calories]. This target of 20% appears to have been consistently met. In a Bristol Superior Court document dated 12/8/89, amendment to the treatment plan was allowed for the use of the Specialized Food Program. It was decreed that "[redacted] will be examined by a qualified physician at least every two weeks, and lab work shall be conducted as medically indicated...". On page 7 of this document it is stated that: "If the minimum daily total of 2500 calories...has not been ingested by 7:00 P.M., then the balance necessary to bring the total staple-food calories eaten to 2500 will be dispensed to [redacted] in the form of non-preferred staple food starting at 7:00 P.M....". Within this document "non-preferred staple food "currently refers to a plate of bland food consisting of mashed potatoes, chicken and spinach at room temperature".

Excerpted from the Program Description dated 9/26/90:

1. "IF [redacted]'S WEIGHT FALLS TO 108# OR BELOW, PLEASE NOTIFY HER CASE MANAGER!"

2. Aversive consequences included: ammonia, vapor spray, taste, water spray, spanks, pinches, and board.

In a document signed by [redacted], M.D., dated 9/18/90, current weight was noted as 108#. "Special Food Program Line 80% 96". On a Food Program visit to [redacted] M.D., no weight was noted. He stated that [redacted] is doing well in the special food program". Dr [redacted] also saw [redacted] 10/7/90 for a toe infection and prescribed Dicloxacillin 250 mgm po qid for ten days. On 10/13/90 Dr. [redacted] again saw [redacted] for "infection on the right cheek secondary to scrapes". He prescribed Erythromycin for ten days. On 10/18/90 and 11/1/90 Dr. [redacted] stated: [redacted] is doing well on special food program". No weights were documented. Dr. [redacted] saw [redacted] on 11/13/90 and stated: "Spec. food red line 100. Present weight 104". On 11/28/90 Dr. [redacted] wrote: "Present weight 107 lbs. 90% red line 113 lbs. [redacted] is still on the Spec. Food Program but with an increase in calories". No laboratory work was described in any of the above food program evaluations.

EVENTS IMMEDIATELY PRECEDING DEMISE

On 12/17/90 an incident report was completed by the "RC Frenier". This document states that on that date [redacted] "refused dinner and

her fruit. This is not like [redacted]. She looked pale and tired. ... During the night [redacted] kept getting out of bed... She also kept going into the bathroom... She also had attempts to vomit but nothing came out...Her eyes were glassy... I knew she was sick even though she didn't have a fever... On the bus she kept putting her feet on the seat...She had to be carried in [to school]... I asked [redacted] the nurse, to see her immediately".

In a residence document, dated 12/18/90, [redacted] was found in bed and "extremities were blue to purple... She had labored breathing... her eyes were glassy". An ambulance was called and [redacted] was transported to Sturdy Hospital, Attleboro, Massachusetts. She expired in the operating room on December 19, 1990 at 1:45 A.M.

RELEVANT AUTOPSY FINDINGS

Upon admission to the Emergency Room there was a question raised as whether there had been ingestion of a caustic substance. (Prior to the ambulance departure from [redacted]'s residence there had been discussion of the use of aversive therapies and a bottle of a liquid substance removed from the bathroom by a police officer). Autopsy findings were listed as:

I. Sepsis and peritonitis due to perforation of stomach, etiology unknown.

a. History of acute abdomen with viscus rupture.

b. Necrotic anterior stomach wall with approximately 1500 ml of gastric contents in peritoneal cavity.

c. Diffuse peritonitis, microscopic.

d. Foci of acute hemorrhagic ulcerations of mucosa of stomach.

II. Congenital encephalopathy... autism... seizure disorder

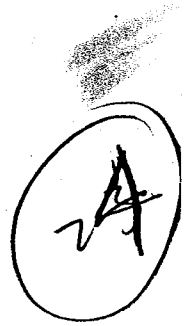
III. Absence of drugs, alcohol or caustic material in various body fluids.

IV. Rape kit analysis reveals no evidence of seminal fluid or sperm.

Other details of the full autopsy include:

1. "... body measures 64 inches and weighs approximately 90 pounds".

2. "A 2 inch area of contusion is present on the anterior aspect of each upper arm. There is a slight greenish discoloration of the skin of the left cheek originating from the left side of the mouth. The buccal mucosa of the mouth and the tongue are unremarkable".



3. "The oropharynx and esophagus are unremarkable. The distal 1/3 of the esopnagus shows slight erythema of the mucosa. There is an 8 cm defect of the distal 1/2 of the anterior wall of the stomach. The stomach contains approximately 20 ml of dark fluid. The gastric mucosa shows a normal rugal pattern and the area surrounding the defect is necrotic while elsewhere the gastric mucosa is erythematous. The external surfaces of the small and large intestines are unremarkable. The appendix is present".

Excerpts from Dr. Weiner's opinion include:

1. Death resulted from sepsis and peritonitis due to perforation of the stomach, etiology unknown.

12

2. There were multiple ulcers of the stomach.

3. The enormous quantity of stomach contents [1200 cc] removed at surgery may have caused or contributed to this event.

4. The perforation of the stomach does not appear to be related to a caustic substance.

5. It cannot be ruled out that a foreign object may in some way precipitated this.

6. The appearance of the stomach and peritoneal cavity suggest that this was a recent event, not more than 1-2 days of duration.

7. There were no injuries to the inside of the mouth or to the lining of the esophagus.

8. The manner of death is natural.

DISCUSSION

This consultant finds multiple extremely troublesome aspects to this case. Of paramount concern is the use of the Special Food Program and the constantly changing parameters for "red line" weights. Significant weight loss resulted from the use of this program. The December 1989 weight of 125 pounds for a height of 64" is well within the acceptable range. I find no grounds for dietary modification based on this weight. By 11/30/90 weight had dipped to 104#. However, the Program Description of 9/26/90 outlined in bold letters that the case manager should be contacted if weight fell to 108# or below.

Not all laboratory tests mandated by the court for the Special Food Program are available. Of note, however, is a December 1989 Annual Medical Evaluation noting a hemoglobin of 14.1 and hematocrit of

42.5. Nutritional consult of January 1990 noted a hemoglobin of 13.5 and hematocrit of 39.5. Although these laboratory changes may be statistically irrelevant, given the type of diet [redacted] was receiving and her continued physical growth, a formal discussion between the physician and dietician should routinely have taken place.

Possible contributory causes of death entertained have been the chronic use of vinegar and jalapeno tastes **used** as aversive therapies. Vinegar, acetic acid, has a pH far above that of the stomach. Literature review (please refer to citations) fails to elicit a correlation between capsicum, an ingredient of chile peppers, and peptic ulcer disease. Moreover, the normal appearance of the lining of the mouth, throat, and upper 2/3 of the esophagus makes such arguments questionable. The use of inhaled ammonia, used as an aversive for [redacted], most typically results in pulmonary sequelae (please refer to citations). From this consultant's perspective, as well as through discussion with the gastroenterology consultant, Dr. Rabb, the use of the prescribed aversives did not contribute to [redacted]'s demise.

Staff's description of [redacted] on 12/17/90 are consistent with an abdominal process. She was "attempting to vomit". The placing of her feet on the seat in the bus is compatible with peritoneal irritation and the autopsy findings of peritonitis. Of note was the description of [redacted]'s several meal refusals, felt by all staff

to be extremely atypical.

DISCUSSION

While autopsy findings were inconclusive for definitive cause of death as perforated ulcer, such a diagnosis is extremely likely. (Please refer to Dr. Rabb's report). Contributory causes of peptic ulcer disease, i.e., cigarette/alcohol abuse, family history, and use of non-steroidal inflammatory agents [note: there was no documentation as to recent Naprosyn use for dysmenorrhea (painful menstrual periods)] are not applicable in this case. As mentioned above, aversive therapies also cannot be implicated in [redacted]'s death. Peptic perforation may be occult. Earlier the signs and symptoms, while indicative of illness, may not have appeared as life threatening. Nevertheless, this consultant has significant issues with the conduct and policies/procedures of BRI's clinical and direct care staff.

1. As noted in the body of this report, [redacted] was allowed "low demands" as prescribed by [redacted], RN, between the hours of 9 AM and 3 PM on December 18. No aversives were applied during this time. However, after 3 PM, over 50 aversives were applied. There was no communication between [redacted] and other staff after 3 PM as to [redacted]'s apparent illness.

2. There is no segregation of BRI students from the general

population during acute illnesses. Students who are deemed "ill" are allowed to rest in their classroom, a situation which could be extremely problematic in the case of communicable disease. Incidentally, it was discovered that there is no specific area for examination by the physician. An empty classroom is utilized as an examination room.

3. Formal nursing documentation policies are non-existent. BRI could not provide any information in this area. In discussion with [redacted] RN, and [redacted] LPN, they both verbalized their concerns re an ongoing abdominal process. However, the only written documentation was a note regarding wax in [redacted] ears. There is no written evidence that [redacted] received the ongoing attention described. These are errors of omission.

4. Adherence to acceptable standards for nursing documentation are not in evidence. For example, there are often no signatures on the nursing documents. In other cases, the signature or stamped name may not be that of the writer.

5. [redacted] has never participated in a formal physical assessment course for nurses. Given the length of time from nursing school graduation and her current clinical responsibilities, such a course should have been mandatory.

6. From discussion with staff, there is no differentiation between licensure and the clinical abilities/responsibilities of perceived "clinical nursing staff". In my discussions with staff, there was no ability on their part to differentiate [redacted] role from that of the other nursing/LPN staff. Moreover, [redacted], when contacted by direct care staff as to an acute presentation by [redacted], requested the staff to wait for [redacted], a certified medication administrator. Such a delay was unnecessary and unwarranted.

7. There is no system in place to insure familiarity with the unique clinical needs of BRI students by local medical providers. Dr. [redacted], whose office is located in Springfield, MA, is considered the "primary care physician". He is extremely dependent upon the observations of [redacted] who as noted previously, has had no formal training in physical assessment.

8. This consultant was not provided any policy, procedure, or information indicative of BRI's cognizance of current acceptable standards of nursing practice.

CONCLUSIONS

[redacted] died from an acute abdominal process. There is no written documentation to support BRI staff's assertions that ongoing, hands-on nursing assessment was performed. Moreover,

despite the "reappearance" of old "behaviors" in the face of an acute illness, staff continued to prescribe aversive therapies to an obviously ill young woman rather than to consider other possible etiologies. [redacted]'s lack of information transfer to the second shift staff regarding [redacted]'s illness delayed medical attention as behaviors, rather than illness, were treated during the late afternoon and evening hours.

Of note is the marked increase in punishments over the 48 hours prior to demise. During the first 16 days of December 1990, an average of 5.6 aversives were administered per day (N=89). On December 17 and December 18, a total of 109 aversives were administered, 20 more than the total for the previous 16 calendar days. During [redacted]'s period of observation (9-3 on 12/20) no aversives were administered. Subsequent to [redacted]'s absence beginning at 3:52 p.m. (to 5 p.m.), aversives were administered (8 FPs, 8 spatula spanks, 3 ammonia inhalants). The perceived need for aversive administration continued until 8:00 p.m. as the staff administered 42 more aversives. Obviously, [redacted]'s presentation was construed as "behavioral" despite previous acknowledgement by day staff that she was ill. The lack of [redacted]'s transfer of relevant health information, coupled with BRI's policy of allowing monitors to increase the hourly number of aversives without a defined procedure as to concomitant variables, resulted in a significant time delay of medical evaluation. Moreover, only [redacted]'s collapse in the bathroom allowed

for recognized illness identification. [redacted]'s request for staff to await [redacted] further delayed necessary acute care interventions. The lack of policies and procedures to assist staff in the differentiation of signs of symptoms of illness from "behaviors" (some in this case not in evidence for several years) can be construed as having a significant impact upon the proper diagnosis, treatment and outcome of this unfortunate death.

Another contributing factor is the current medical support system. [redacted]'s lack of formalized physical assessment training precludes her autonomous role utilizing phone consultation. Moreover, there is no procedure for documentation of the phone discussion at either [redacted]'s or [redacted]'s end.
The lack of acceptable standards for nursing practice and the lack of proximity of familiar medical care providers will continue to place BRI students at significant medical and nursing risk.

December 27, 1994
Date

/s/Carol Walsh
Carol Walsh, R.N.-C, MPH
Health Services Consultant

MENTAL HEALTH

345 COURT ST. • PLYMOUTH, MA 02360

FAX (508) 746-2437

(508) 747-1168

Analysis of [redacted]'s Treatment Records

This report was requested by the Department of Mental Retardation of Massachusetts in its investigation of the death of [redacted] who had been receiving residential and day program services for six years from the Behavior Research Institute in Rhode Island.

The DMR Staff Investigator, Ms. Donna Cabral, requested an analysis of the documents provided by BRI regarding the treatment [redacted] received from the time she was admitted at BRI in Oct. 2, 1984 to the time of her death in Dec. 19, 1990. Ms. Cabral requested answers to a list of questions which focused mainly on the characterization of treatment with aversive stimuli and the evaluation of its appropriateness and effectiveness.

This report was written by Angela Duarte, Ph.D. in consultation with Michael Apolito, Ph.D.

Name: [redacted]

Date of Birth: 2/23/71

Date of Death: 12/19/90 (prior to 3am)

Date of Admission at BRI: 10/2/1984

Length of time at BRI: 6 years 2 months 16 days

Previous Residential Placements: Home (1971-1978); Bradley Children's Psychiatric Hospital (1978-1984).

Diagnosis: Severe Mental Retardation

BRIEF HISTORY:

At the time of her death (Dec. 19, 1990) [redacted] was 19 years old and had been receiving Residential and Day Program services from the Behavior Research Institute in Providence, Rhode Island, since she was 13 years-old (Oct. 2, 1984).

According to the records reviewed, from birth to age 6 [redacted] lived at home. From 1974 to 1976 [redacted] received Day Program services from I.H.-Schwartz Clinic ([redacted] left because this program was considered inadequate); [redacted] was enrolled in the Community Clinical Nursery from 1976 to 1977 and left when the one-year program ended; [redacted] was then enrolled at the Project Orient Nursery where she stayed until she aged out. In 1978, at age 7, she was placed at the Bradley Children's Psychiatric Hospital for Residential and Day Program services where she stayed until her placement at BRI in October 2, 1984.

Treatment

Target Inappropriate Behaviors

The earliest BRI record examined on [redacted]'s behaviors was dated Oct. 8, 1984. A Monthly Tally Sheet for October of 1984 indicates that data was collected on 36 inappropriate behaviors for 19 days from October 8 through October 31. The frequency of each behavior during that period is shown in parentheses: Aggressive acts (251); Bang (821); Bite objects (2); Body rub (10 - all in 2 days); Clap (3); Click (16 - all in 2 days); Clothes off (mostly shoes off - 216); Destroy (262); Drool (139); Eat inedibles (137); Handplay (223); Hands to head (371); Head shakes (218); Inappropriate touch (118); Inappropriate Urination/Defecation (11; 10 days of no occurrences); Jump (8); Kick objects (0); Manipulate (921); Mouth movement (92); Noise (952); Object to mouth (135); Ritual (22); Rock (238); Scream (878); Smear (266); Silly laugh (31: 30 in her first day); Stump feet (2); Steal (95); Tap (45); Throw (105); Walkaway (139); Self abuse (565); Spit (121); Lookaway (99); Out of seat (396); Stop work (197).

In November, seven behaviors were dropped from that list, and "Refuse" was added (14 in 6/31 days) for a total of 30 target inappropriate behaviors presented here in alphabetic order: Aggression acts, Bang, Clothes off, Destroy, Drool, Eat inedibles, Handplay, Hands to head, Head shake, Inappropriate touch, Inappropriate Urination and Defecation, Jump, Lookaway, Manipulate, Mouth movements,

Noise, Objects to mouth, Out of seat, Ritual, Rock, Scream, Self abuse, Smear, Spit, Steal, Stop work, Tap, Walkaway, Refuse, Body rub.

The high number of inappropriate behaviors identified above might be explained by BRI's general criterion in deciding what behaviors are considered inappropriate:

> "It is our policy at BRI to try to eliminate all the bizarre and inappropriate behaviors-not merely self-injurious, other injurious, or property-destructive behaviors.
>
> At BRI, decisions as to what constitutes bizarre or inappropriate behavior are initially made by the BRI education and treatment staff based on a kind of 'Howard Johnson's' test. Behavior that would embarrass a typical parent of a normal child if that behavior occurred in a Howard Johnson's Restaurant would be judged to be inappropriate." (Permission Package, Section A: Permission for Selection of Behavior for Treatment, p.10)

It is important to note, however, that because of its intrusive nature, punishment procedures are typically used to treat severe behaviors that have been shown to be resistant to less intrusive forms of treatment. No records were seen showing that positive-only procedures were attempted following the collection of baseline data and prior to the introduction of punishment procedures in the end of October of 1984 ([redacted] was admitted at BRI on Oct. 2, 1984).

Punishment Procedures

Following is a list of the punishing stimuli used with [redacted] The descriptions were obtained from BRI's records:

Water Spray I: The student is sprayed on the face or neck with water from a spray bottle. The water may be chilled by the insertion of ice in the bottle.

Taste Aversives: One or more unpleasant foods or tastes (e.g., vinegar, lemon juice, vanilla extract, mustard, Listerine, horseradish, hot pepper, hot sauce, salt solution, anti-nail biting substances) are applied to the student's tongue or lips immediately after the occurrence of an inappropriate behavior. Depending on the substance used, the taste aversives may be applied with a spray bottle, a mustard dispenser, a syringe, an oven baster, or an eye dropper. Alternatively, a portion of disliked food (e.g., egg salad for a student who dislikes eggs) is given to the student.

Ammonia: Ammonia capsules are broken and waived back and forth under the student's nose. Sometimes the ammonia is squeezed inside the student's nostrils.

Spank: One or a specified number of spanks is applied with the staff member's bare hand to the bare skin of the student's hands, arms, legs, thighs or buttocks. If the spank is applied to the buttocks, then the spank is administered by lifting a flap of the student's shorts, whenever possible. Alternatively, the staff member slips the

student's pants or shorts down over his/her buttocks just far enough to expose the area that will be spanked. Care is taken not to expose the genital area.

The student may be placed in a secure position that prevents any significant movement while the spank is being administered. In this "spank position", the student is facing the staff member and his/her head is placed between the staff member's knees where the student's head is held securely. The student's hands are brought up behind his/her back, and the staff member holds the student's hands in that position. After the spanking, the student's pants are pulled back up by the staff member or student, and the student's hands and head are released.

The student may also be placed in the "spank position" when the thighs are to be spanked.

Spatula Spank: Same as above, except spank is administered with a flat rubber spatula.

Muscle Squeeze: The muscle is held firmly between the staff member's thumb and fingers. Pressure is applied in an intermittent manner, in order to cause the muscle or tendon to snap back and forth, moving inside and then outside the grip of the staff member's finger and thumb. The muscle used may be in one or more of the following areas: the calves, the inner or outer thighs, the pectoral area (in males only), the upper arms, the triceps, or the area between the neck and the shoulder. In some cases, the location of the squeeze may be rotated to several areas in order to minimize bruising or

adaptation in any one area, and/or to maintain the element of surprise.

As another example, when a squeeze is applied to the student's cheek or mouth area, the thumb and finger are placed on both sides of the student's mouth, and a firm squeeze is administered. In some instances, the squeeze may be held until the inappropriate behavior stops.

Finger Pinch: The end of the student's finger is held between the staff member's index finger and thumb. The staff member applies pressure with his/her thumbnail, or with the side edge of a pencil or pen, to the base of the student's fingernail for a specified period of time.

Hand Squeeze: The staff member stands or walks beside the student and holds his/her hands and squeezes it firmly.

Wrist Squeeze: The staff member squeezes the student's wrist by moving and pressing a thumb or finger across the inner side of the student's wrist.

BCS - Brief Cold Shower: The student stands undressed in a shower stall, and the shower or a hose is turned on for 5 minutes or less.

Water Spray III: Cold water is poured over the student's head and/or body.

Air Spray II: No description available.

Restraints: Helmet and 4-point board. No description available.

Effectiveness of Treatment for Specific Behaviors

An assessment of the effects of treatment on individual behaviors is not possible. Even though baseline data was collected on 36 individual behaviors, in January of 1985 all behaviors were grouped in 9 categories: Aggression; Destroy; Inappropriate Motion; Inappropriate U/D; Inappropriate Verbal; Non-compliance; Self-abuse; Stereotypic Behaviors; and Work Interference.

From the moment the behavioral categories were created (e.g., Health Dangerous Behavior), it appears that BRI ceased data collection on the frequency of each specific behavior, and they began to report only the totals for each set/category of behaviors. The problem with this practice is that it does not allow the evaluation of improvements or worsening of each behavioral component over time.

The problem is aggravated by the fact that throughout the years, new behavioral categories were added, some categories were renamed or dropped, new behaviors were identified and added to the existing categories, or a new one was started, and old or new behaviors were switched from one category to another.

Such unsystematic changes make it impossible to determine which specific behavior was or was not being affected by treatment.

If the components of the behavior categories were constant, one could at least assess the effects of treatment

for the category as a whole. However, when individual behaviors with varying individual frequencies are unsystematically shifted across behavior categories such assessment becomes impossible.

Changes in treatment conditions or on the components of the categories were usually reported in the following manner:

"Program Changes

8/15/90:

Aggressive: Consequence changed to Board, Visual Screen Goggles 15 minutes, 3 (int.) Spatula Spanks, Ammonia, Finger Pinch.

8/19/90:

HDB (Steal): Drop as separate behavior.

HDB (other): Add "steal" to operational definition.

HDB (Inap. Motion): Drop as a separate behavior.

HDB (Other): Add "inappropriate motion" to operational definition.

HDB (Refuse Fire Alarm): Drop as separate behavior.

HDB (Other): Add "refuse to leave building in response to a fire alarm" to operational definition.

Ed/Soc. (Inap. Sexual Inter.): Drop as separate behavior.

Ed/Soc Inter.: Add "inappropriate sexual interaction" to operational definition.

Ed/Soc (Work Inter): Drop as separate behavior.

Ed/Soc Inter.: Add "stop work" to operational definition.

Ed/Soc. Stereotypic: Rename Educationally/Socially Interfering behavior." (BRI-Program Update, October 13, 1990, p.2-3).

Even when reported in the charts, the changes did not include any information on the individual frequency of the behaviors that were being added or removed from the categories.

Overall Treatment Effectiveness

Even though it was not possible to evaluate the effects of treatment on each target behavior or behavior category, following is an assessment of the overall effects of treatment on the total number of targeted inappropriate behaviors:

The records indicate that aversive stimuli were introduced to [redacted]'s treatment shortly after her admission at BRI. The Weekly Behavior Chart for the behavior Destroy (Tear paper, throws or spills objects from the table) shows that Water Spray was introduced by the end of October of 1984 and the November Tally Sheet show that Taste aversives and Ammonia were introduced in November 22, 1984.

It is puzzling that applications of Ammonia and Taste Aversives were introduced in the end of November, when [redacted]'s inappropriate behaviors were showing a decelerating trend from October to November when "No" and "Water Sprays" were the only consequences. The data also indicate that when

Ammonia and Taste aversives were introduced, the total level of inappropriate behaviors immediately increased by 45%, from 6,584 in November to 9,543 in December.

A data analysis would suggest returning to the previous intervention and/or revising the use of positive procedures. Instead, the records indicate that the use of Taste aversives and Ammonia were continued and in January of 1985 six new types of aversive stimuli were added: Spank, Muscle Squeezes, Finger Pinches, Hand Squeezes, Wrist Squeezes, and Brief Cold Showers (Table 1), which led to a temporary decrease in the level of inappropriate behaviors followed by a drastic increase.

From January of 1985 to August of 1985, [redacted] received increasingly higher doses of punishment. There were months in which she received as many as 214 Ammonia Applications, 486 Muscle Squeezes, 691 Spankings, 707 Hand and Wrist Squeezes, 1,218 Finger Pinches, and 4,155 Taste Aversive Applications. The high number of taste aversives and ammonia applications is specially troublesome in light of the lack of research that analyze the effects of some of these substances on the organism.

In August of 1985 [redacted] received 5,754 punishments: 4,155 Taste Aversives (3,078 from Aug. 22 to Aug. 31); 214 Ammonia Applications; 114 Spankings; 154 Hands and Wrists Squeezes; 294 Muscle Squeezes; 741 Finger Pinches; and in 48 hours (Aug. 9 and 10), she received 82 Brief Cold Showers.

Figure 1 shows the increasingly high levels of combined aversive stimuli received by [redacted] from Oct. 84 to Sept. 85.

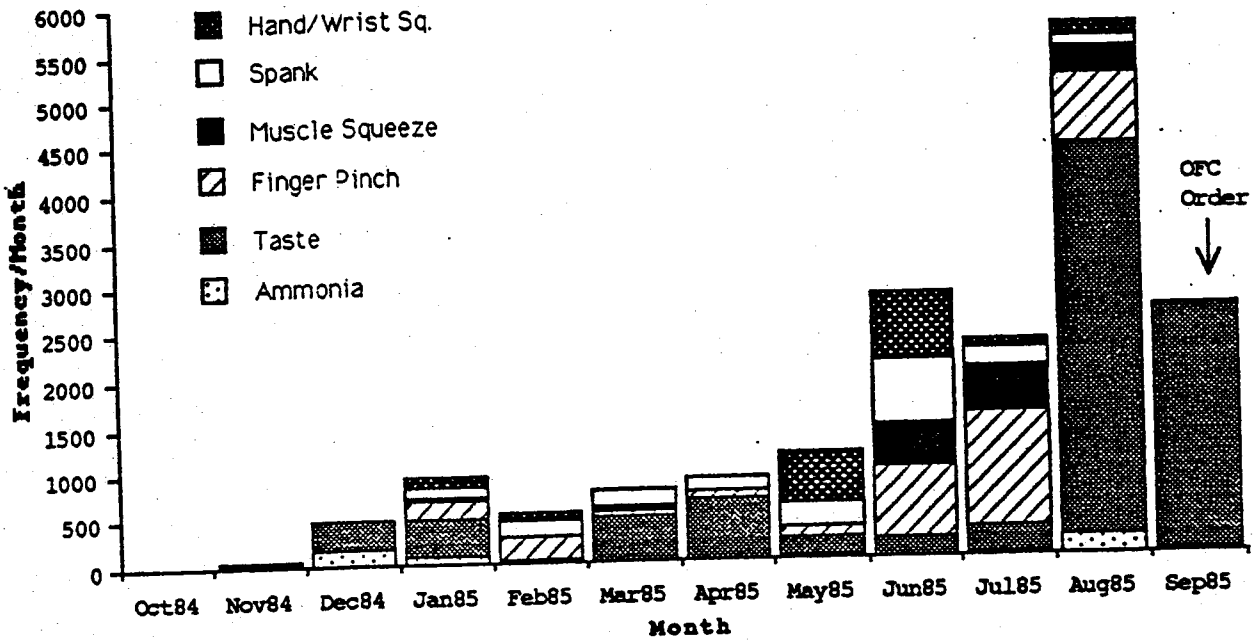


Figure 1. Combined Aversive Stimuli.

Figures 2, 3, and 4, isolate the frequency of Taste Aversives, Ammonia Applications, and Physical Punishment.

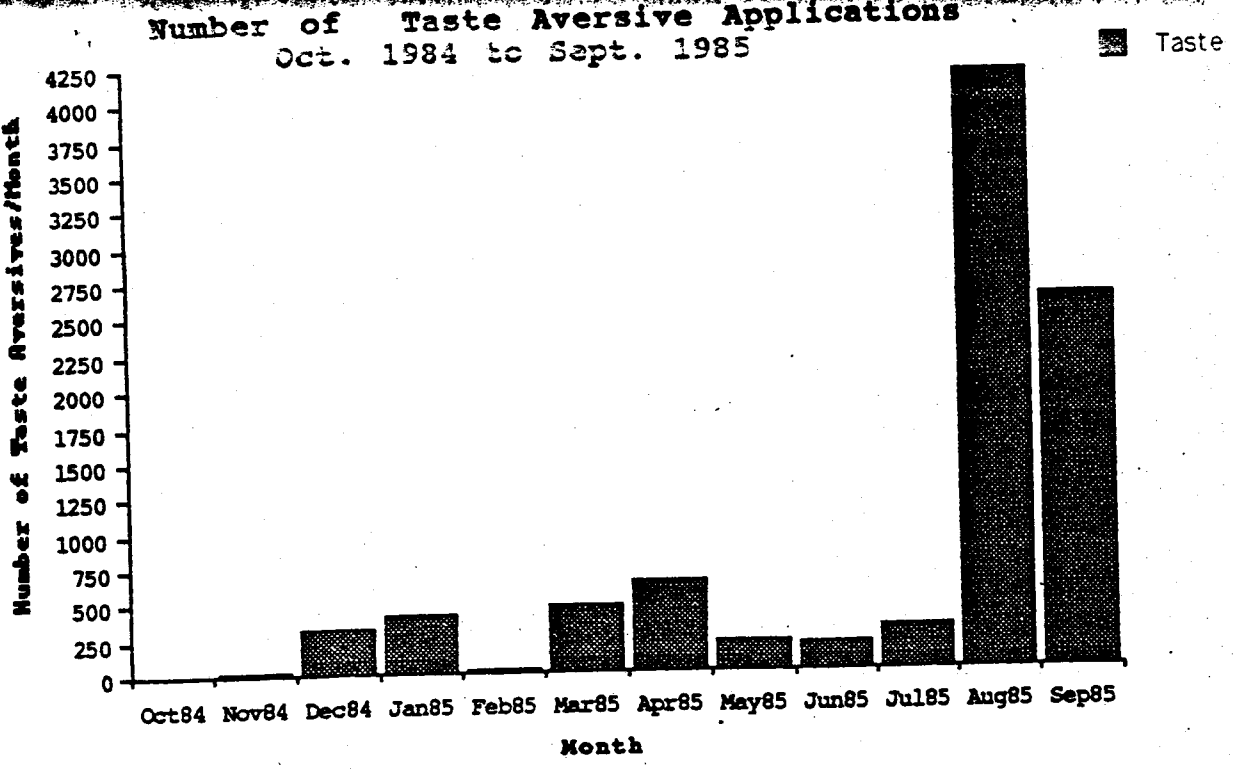


Figure 2. Taste Aversive Applications.

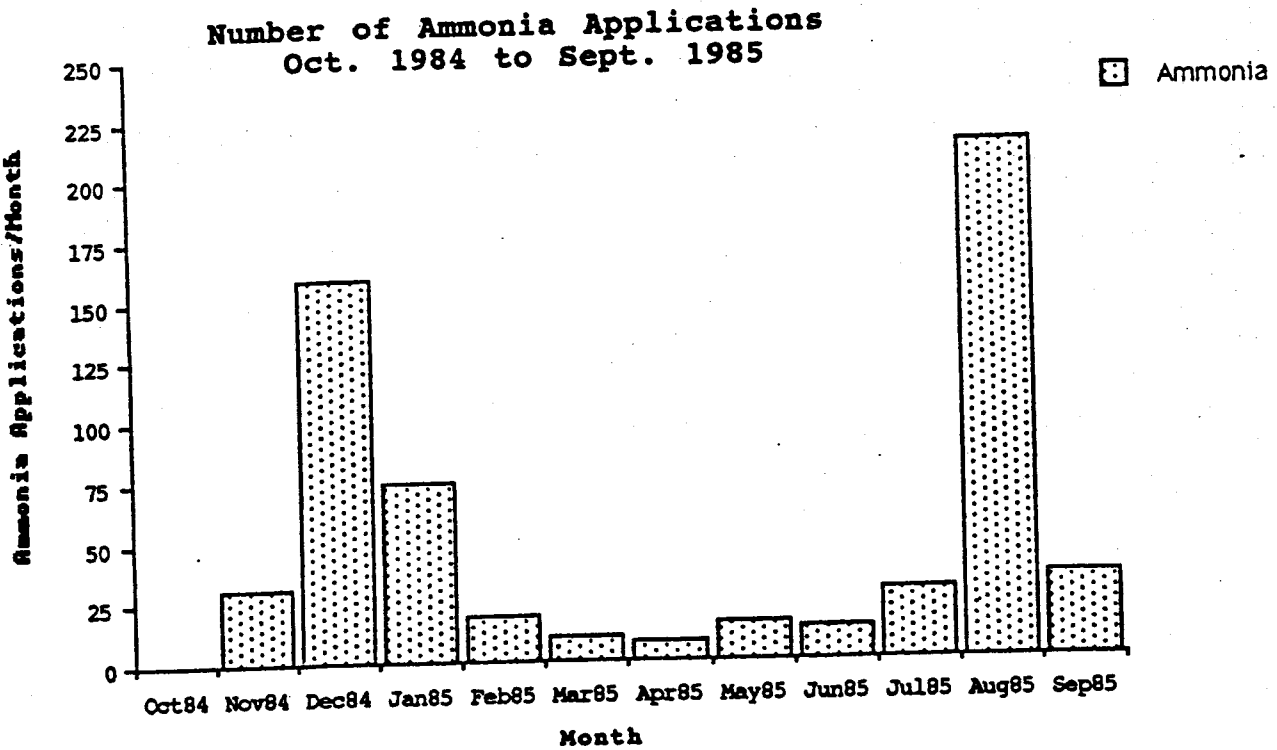


Figure 3. Ammonia Applications Oct.84-Sept.85

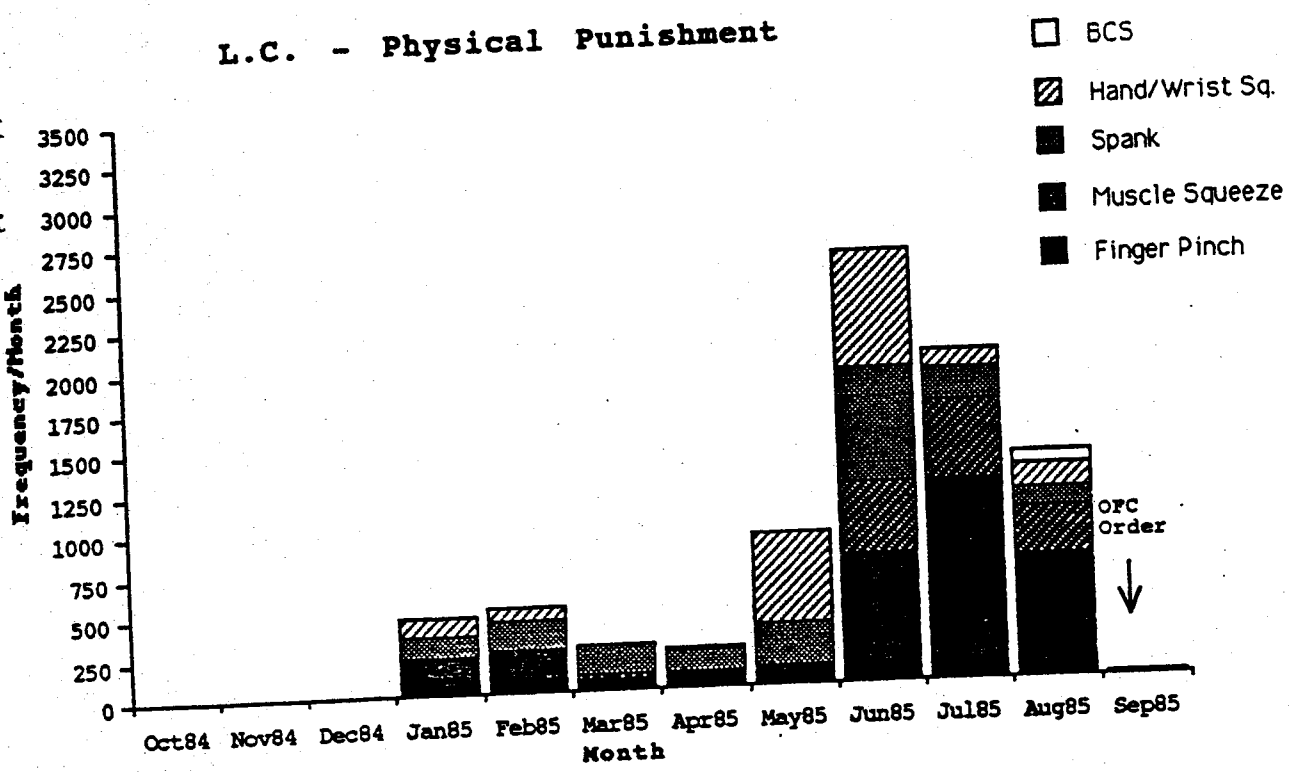


Figure 4. Physical Punishments.

Figure 5 shows that the total number of inappropriate behaviors were temporarily reduced: 6,804 in January/85; 4,222 in February/85; 3,323 in March/85; and 2,811 in April/85.

By May/85, however, the number of inappropriate behaviors started increasing again to reach a level 500% worse than baseline: 3,077 in May/85; 5,586 in June/85; 10,055 in July/85; and 31,627 in August/85).

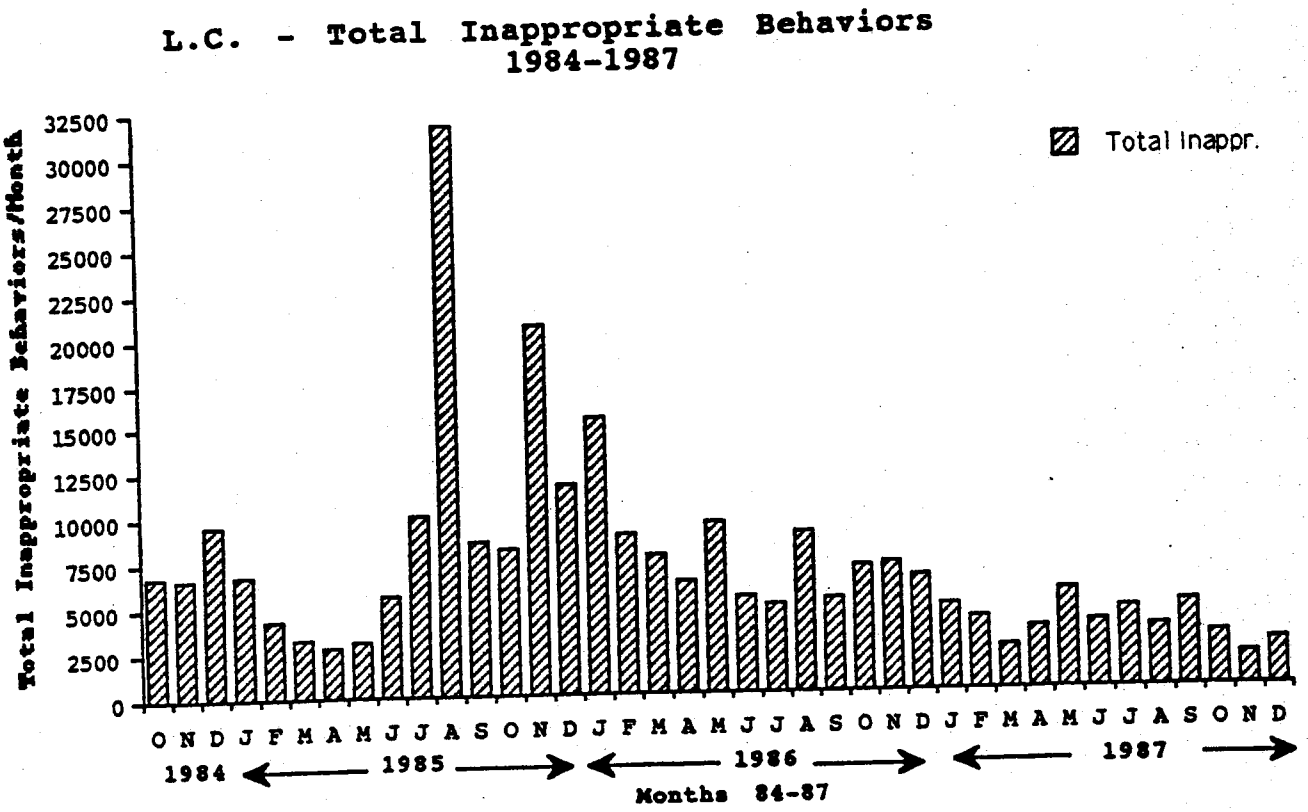


Figure 5. Number of Inappropriate Behaviors per Month.

Apparently, in September of 1985, BRI was prohibited from using physical punishments such as Finger Pinches, Muscle Squeezes, Spank, Hand Squeezes, and Wrist Squeezes.

Figure 5 also shows that as these forms of physical punishment were dropped from treatment, the frequency of Linda's inappropriate behaviors decreased substantially.

These effects suggest that the punishment procedures might have been producing the increase in the frequency of inappropriate behaviors. This would be consistent with the literature in applied behavior analysis:

As Martin and Pear, 1988 explained:

> "Strong punishment tends to elicit undesirable aggressive behavior. Experiments with animals show that painful stimuli cause them to attack other animals-even though these other animals had nothing to do with inflicting the painful stimuli (Azrin, 1967). If this finding also applies to humans, then we should not be surprised to observe individuals who have just been punished attacking other individuals" (p.195).

Indeed, when painful stimuli were reintroduced in [redacted]'s treatment in October of 1987, it seemed to have little effect on [redacted]s aggressive behaviors. Following are some excerpts taken from BRI's Quarterly Program Updates on the category Aggression, dated October 1989 to October of 1990.

Oct 14, 1989

Aggressive Behavior: "The frequency of this behavior fluctuated between two and 30 occurrences per week during this reporting period." "Overall, [redacted]'s inappropriate behaviors are still occurring at an unacceptably high rate..."

Program Changes: On December 14, 1989 Specialized Food was added to [redacted]'s program.

Jan 13, 1990

Aggressive Behavior: "The frequency of this behavior fluctuated between 17 and 52 occurrences per week during this reporting period. There was an overall acceleration in this behavior...We remain concerned about the increase in her Aggression and the high frequencies of some of her behaviors. We will continue to monitor this and make any necessary modifications".

April 14, 1990

Aggressive Behavior: "The frequency of this behavior fluctuated between 12 and 83 occurrences per week during this reporting period."

Program changes (1/26/90): " Change consequences to Spatula Spank; Add 'grabbing others' to operational definition; Add to Multi-day DRO contract."

July 14, 1990

Aggressive Behavior: "The frequency of this behavior fluctuated between 11 and 62 occurrences per week during this reporting period."

October 13, 1990

Aggressive Behavior: "The frequency of this behavior fluctuated between five and 120 occurrences per week during this reporting period."

Figure 6 displays the aversive stimuli administered to [redacted] from 1984 to 1990.

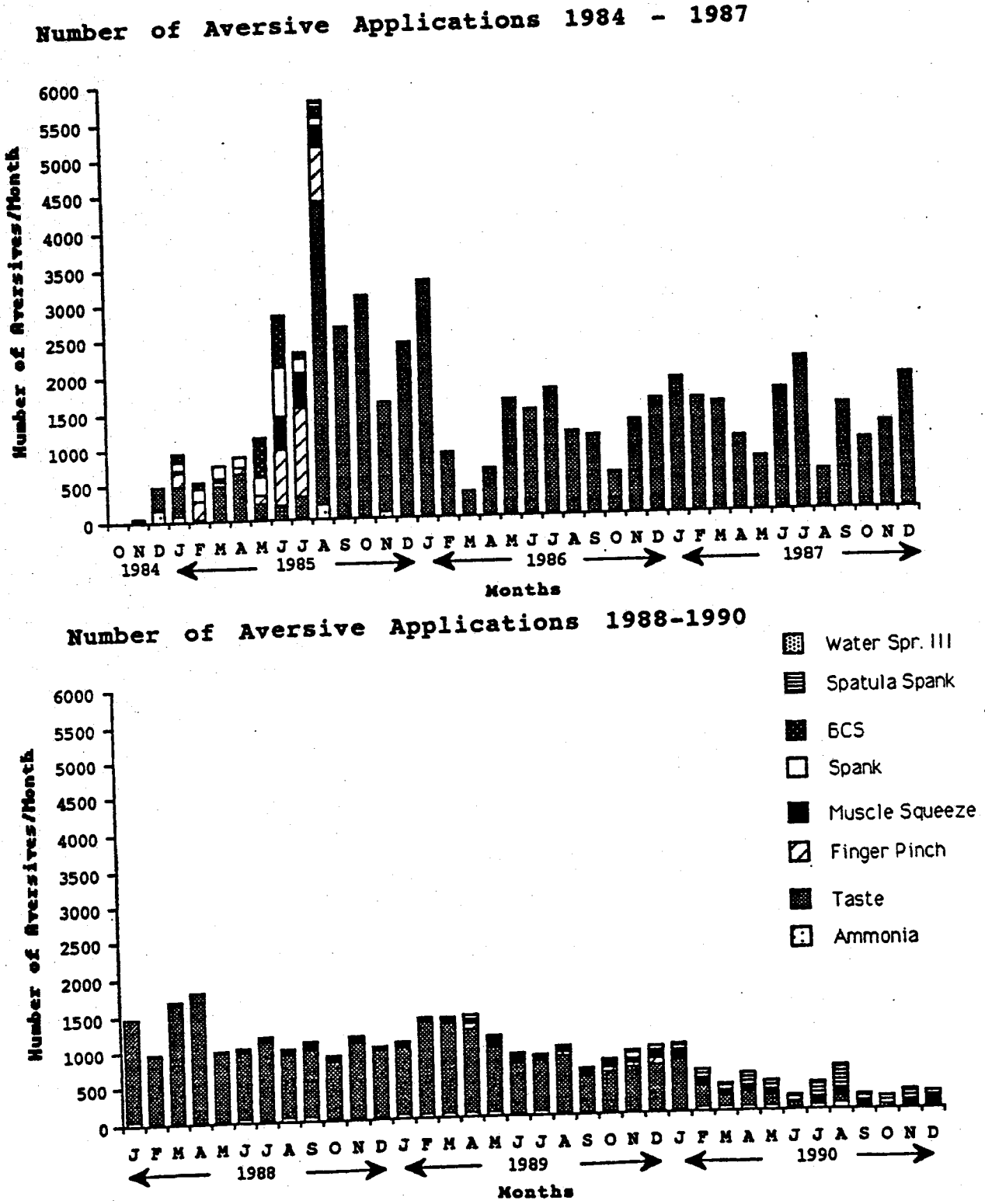


Figure 6. Total Number of Aversive Applications.

Figure 7 shows that the most substantial decrease in the overall level of inappropriate behaviors was observed when physical punishment was discontinued from 09/85 to 10/87 and that the reintroduction of physical punishment did not substantially decrease the frequency of target behaviors.

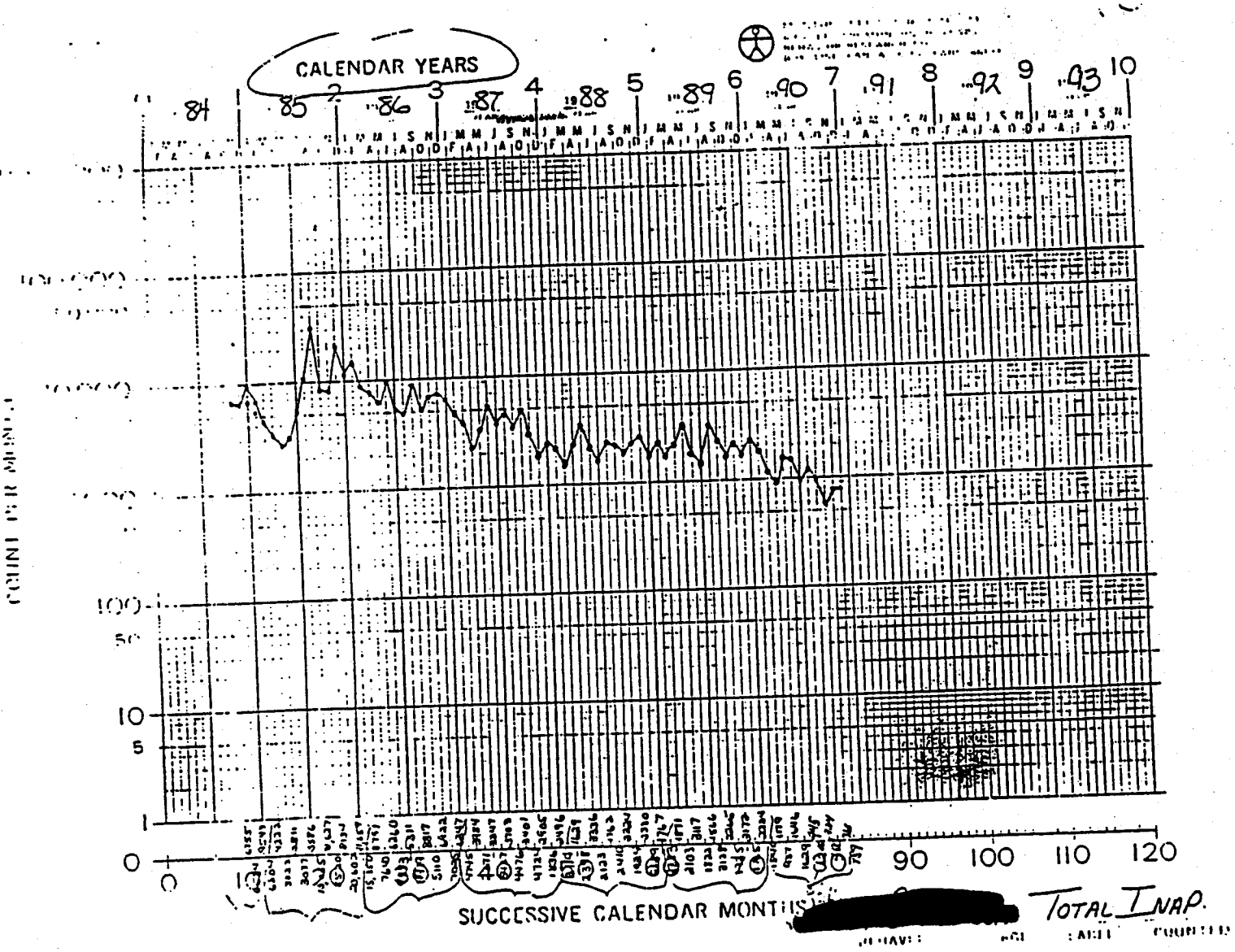


Figure 7. Total Number of Inappropriate Behaviors (BRI's record).

Unfortunately, as explained earlier, it is impossible, to determine whether the behaviors that were suppressed when physical punishment was discontinued were minor problems such as "Silly laughing" or more serious problems such as "Bite".

Perhaps the overall effectiveness of treatment was well characterized by BRI's own statement in the July/1990 Program Update:

> "During this reporting period, there has been only minimal improvement in the frequency of [redacted]s most problematic behaviors. Although a slight decelerating trend was recognized for Aggressive Behavior, Destroying and Health Dangerous Behavior (Other), <u>all continue to be exhibited at an unacceptable rate of occurrence</u> [emphasis added]."

If this statement is accurate and [redacted] most severe behavior problems were still occurring at unacceptable rate, it is possible that (a) the punishment procedures were not being implemented appropriately or (b) punishment procedures were not an effective form of treatment for [redacted] and should not have been continued for 6 years.

Treatment conditions in [redacted] last 3 days:

Ms. Cabral, the DMR investigator, requested a special analysis of the documents describing [redacted]'s treatment and activities just prior to her death. Following is a chronological account of some of the events that took place during [redacted]'s last 3 days. This account is based on the following documents: a) A Therapy Note written by [redacted] who was one of BRI's residence supervisor; (b) behavioral treatment information recorded in three daily data sheets (12/16/90, 12/17/90, and 12/18/90); and (c) Incident Report provided by the Attleboro Police Department.

Sections of the Attleboro Police Department investigative report reads:

> "[redacted] said she first noticed [redacted] acting peculiar at 7pm on the 17th. Her strange behavior led her to believe [redacted] was not well and reported her to the school nurse when they arrived [at school]. Ms. [redacted] also made a written report concerning [redacted]'s behavior [Therapy Note, dated 12/17/90]".

The copy of the Therapy Note written by [redacted] was partially illegible. Following is an excerpt from it:

> "[redacted] refused her dinner ... This is not like [redacted] She looked pale and tired. I put [redacted] to bed at ....pm. During the night [redacted] kept getting out of bed walking to the ..... going back to bed. She also kept going into the bathroom. [redacted] had .... at 9:00,

10:00, 11:00,.... She also had attempts to vomit but nothing came out. [redacted] never has OOB [Out Of Bed] and was very lost, looking all around like she didn't know where she was at. Her eyes were glassy..."

It is disturbing that even though staff had identified [redacted]'s behavior as that of someone who might be ill , the punishment components of BRI's treatment were carried out throughout the night. BRI's records indicate that overnight [redacted] was spanked 8 times, had muscle squeezes (the number is illegible), was administered ammonia inhalants, and had taste aversives (vinegar mix, jalapeno pepper, or hot sauce?) administered several times.

In the morning (Dec. 18th), [redacted] was apparently taken to school.

"[redacted] the [redacted] took her temperature which was 98.4 degrees. [redacted] said she notified [redacted] (sic), the [redacted] about [redacted] It was decided that she remain in the care of the school nurse for the rest of the day. [redacted] said that [redacted] was responding to treatment and was comfortable the rest of the day. [redacted] also said that [redacted] takes no medication" (Attleboro Police Dept., Supplementary Report, p.B3).

BRI's records indicate that Punishment procedures were not used between 10am and 3:52pm. After that, however, within a few hours, [redacted] received a high number of punishing applications:

At 3:52 she was administered an ammonia inhalant; between 4pm and 5pm she was spanked with a spatula 8 times, had 8 finger pinches, and was administered ammonia inhalants again. Each hour after that the punishing applications were continued so that by 7pm [redacted] had received 8 spatula spankings, 27 finger pinches, and 14 muscle squeezes, and several ammonia and taste aversive applications.

At 6:45pm staff had noted that [redacted] "was not herself". Yet, in the next hour (7pm-8pm) she was spanked with a spatula 5 times, was finger pinched 2 times, was administered an ammonia inhalant at 7:40pm and may have had other aversive applications (nature and number are illegible).

Thus, between 3:52pm and 8pm [redacted] had been physically punished at least 56 times (13 spatula spankings, 29 finger pinches and 14 muscle squeezes). She also received several applications of taste aversives and at least 5 ammonia inhalations.

According to the records, at 8pm [redacted] noticed that [redacted]s eyes were glassy and that her pupils were dilated and she called the school nurse. After another staff arrived at the house and examined [redacted] the Fire Department was called and [redacted] was transported by ambulance to the hospital where she died within a few hours.

CONCLUSION

The records that were made available for analysis indicated several areas of concern:

(1) Punishment procedures are typically used to address severe behavior problems. The vast majority of [redacted]'s behaviors targeted for treatment with punishment did not appear to be severe enough to warrant such intrusive form of treatment.

2) Punishment procedures were introduced a few weeks after [redacted]'s admission to BRI, targeting a wide range of behaviors that might have responded well to positive approaches if those had been attempted for a reasonable period of time. (The charts examined did not show formal positive approaches being attempted to address [redacted]'s behavior problems prior to the introduction of punishment.)

(3) Punishment procedures are typically used to quickly and substantially reduce or suppress the frequency of inappropriate behaviors. Such results were not observed in [redacted]'s records.

[redacted] was exposed to treatment with punishment for six years and BRI's own reports indicated that the major behavior problems were still occurring at unacceptable rates. These results suggest that either the punishment procedures were not implemented appropriately or that punishment was not an effective form of treatment for [redacted]

(4) [redacted]s records indicate that BRI's data collection and data reporting system (categorization of behaviors and subsequent switching of behaviors across categories) make it impossible for the provider, clinicians, internal or external monitors, to thoroughly evaluate the effect, if any, of aversive and non-aversive treatment on each of the client's target behaviors.

Such practice would be disturbing independent of the form of treatment used, but it is even more so when punishing procedures as intrusive as those [redacted] received, are being used.

(5) Most disturbing of all was to find that a high number of punishment procedures were administered to [redacted] just prior to her death, after staff had already formally reported that she appeared to be ill for two consecutive days.

Angela M. M. Duarte

Angela M. M. Duarte, Ph.D.

Behavioral Psychologist

NUTRITION CONSULTANT'S REPORT

CASE # 05-93-TNTN-397

PREPARED BY: DEBORAH DESSAINT MS, RD, LDN

JUNE 10, 1994

This report was prepared with information provided by Investigator Donna Cabral.

Preparer: Deborah Dessaint

Date: 6-10-94

SPECIALIZED FOOD PROGRAM

From a nutritional standpoint, there are grave concerns associated with the Specialized Food Program as described within the documents of the Behavioral Research Institute (BRI) and initiated with [redacted] on December 14, 1989. Of primary concern is that the program did not guarantee that [redacted] was provided enough kilocalories to maintain her health. The body cannot sustain health and optimal wellness without adequate calories, its source of fuel. However, on this food program, there existed the possibility that [redacted] may have only received 800 kilocalories a day, for extended periods of time.

Kilocalories (often abbreviated as calories) are the units of energy that the body uses and transforms to keep itself alive. Each individual requires a certain number of calories, based on their body size. This number of calories can be determined numerically.

At the time that [redacted] was put on the Specialized Food Program, she was 5'4" tall and weighed approximately 125 pounds. Her Ideal Body Weight (IBW) for her height was 120 pounds (100% IBW) plus 12 pounds (110% IBW) or minus 12 pounds (90% IBW). However, weight loss was sought for [redacted] due to weight gain. I strongly question the rationale for putting [redacted] on a weight loss regimen, as she was at no time over her Ideal Body Weight, the weight that experts have determined to be optimal for her age and height. However, the nutritionist identified 112 pounds, the midline between 90% IBW and 100% IBW as the weight goal. The Court ordered that [redacted]'s weight was not to fall below 90% IBW or 108 pounds, referred to as the red line.

Based on known methods of calculating energy expenditure and caloric needs, [redacted] would have needed at least approximately 1737 calories (1) and 39 grams of protein (2) per day to maintain her at the red line of 108 pounds.

[redacted]'s caloric level was 1500 calories per day. However, the Specialized Food Program allowed for the dispensing of only 20%, or 300 calories, based on her behavior. Therefore, [redacted] may have gotten only 300 calories per day for extended periods if her behavior was uncooperative. These calories were not supplemented with vitamins and minerals.

It is not recommended that anyone consume less than 1000 calories per day, or do so without vitamin and mineral supplementation. Vitamins and minerals are nutrients that are vital to body functions. The National Academy of Sciences, after much research, publishes a list of vitamins and minerals and the amounts required by the human body. These Recommended Dietary Allowances (RDAs) are received from food. However, with the amount of food provided by 300 calories, it is impossible to meet the RDAs. Even the much publicized Very Low Calorie Diets (VLCDs) or Modified Protein Fasts, in which the goal is to induce extreme and rapid weight loss in a modestly to morbidly obese person, provide at least 400-800 calories/day and are always supplemented with multivitamins and minerals. Persons taking part in these diets are also closely monitored by physicians with laboratory values and other measures on a weekly basis. The discussion of VLCDs serves to illustrate that only in the most stringent of circumstances is the caloric intake of a person in a clinical setting allowed to fall so low, and never for someone who is at their IBW.

That there even existed the slightest possibility that [redacted] would not receive enough calories to meet her daily needs over periods of time is a serious flaw in the design of the Specialized Food Program. From a nutritional

1. Harris Benedict equation
2. Based on .8 grams/kilogram body weight

standpoint, all clients should be provided with adequate calories, regardless

of behavior. Prior to 12-14-89, the Contingent Food Program that [redacted] was on had a safeguard provision called a "make up". This ensured that [redacted] received her full caloric intake for the day, non-contingent upon behavior. It is my professional opinion that this provision should not have been removed.

The BRI nutritionist stated that she never had input into the implementation of the Specialized Food Program and definitely did not agree with the caloric level of 20% of daily calories, especially with those clients on lower caloric levels. She reports that she addressed the issue that 20% of calories was not adequate with the administrators at BRI. The nutritionist noted reviewing food records that are currently unavailable, and states that she doesn't remember being concerned with the number of calories [redacted] was receiving.

Another concern regarding Linda when she was on the Specialized Food Program is that of the red line; the weight at which [redacted] was not to fall below. The court ordered in July of 1989 that the red line be maintained at 90% IBW or 108 pounds. In April of 1990 the red line on [redacted]'s weight charts was reduced to 80% IBW or 96 pounds. The nutritionist reports that she never knew of the court order and never approved a change; the change was initiated by the director. She also states that after some discussion between the director and a physician, the red line was changed to 87.5%. It is also this level that is referred to in an informational brochure about BRI dated June 1993. Nutritionally, 87.5% IBW is low. To strive for a percentage of IBW that is normally associated with mild nutritional depletion is inconsistent with optimal nutritional status. The nutritionist states that she ignored the 87.5% IBW, and continued to use 90% IBW as her guide. However, by May of 1990, [redacted] had started to drop below her red line. In that 5 months, [redacted] lost 18 pounds. She continued to hover around her first red line until the time of her death.

On December 11, 1990, [redacted]'s calories were increased to promote weight gain. There is some discrepancy regarding the caloric level, as the nutritionist states that [redacted] was increased to 2000 calories, but the food intake records indicate that [redacted] was increased to 3000 calories. The reason for the increase was that [redacted] had grown 1 inch. That made her IBW 125 pounds plus 12.5 pounds (110% IBW) or minus 12.5 pounds (90% IBW). Thus her red line increased to 113 pounds. At 5'5" [redacted] caloric needs increased to approximately 1771 calories (1) and 41 grams of protein (2) per day to maintain 113 pounds. Therefore, at the time of her death, [redacted] was 7 pounds below her new red line.

It is interesting that BRI used ketone testing with the students on the Specialized Food Program. Ketone formation is an adaptive process the body assumes in response to not receiving enough energy. Ketones are products of fat breakdown. The body breaks down fat for energy, to spare the more vital proteins that the body would prefer to use as energy. When ketones build up, they spill into the urine. Excessive ketone development is not a desirable state, because of the potential side effects associated with ketosis. If ketones build up in the blood, they could cause the blood to become too acidic; leading to possible coma and death. A system was set up to address positive ketone tests, such as the administration of orange juice etc. However, ketone testing is not routine, and is usually done only when it is suspected that someone is not getting enough calories. The nutritionist supports this assertion also. That BRI tested for ketones indicates an awareness of the potential side effects of the Specialized Food Program. Any other comment is impossible, as the records of the ketone testing are unavailable.

Overall, there are inherent problems with the Specialized Food Program

that [redacted] was on, from a nutritional point of view. However, further comment and investigation is hindered by the unavailability of records pertinent to the above discussion. For example, the nutritionist reports, and BRI literature states that Food Intake Records were kept. However, the only food records available are for the month before [redacted] died. Further, although staff reports that ketone testing was done on [redacted] those records are also unavailable. In addition, the nutritionist reports that she filled out a nutrition consult sheet every week, but those are also unavailable. If these records are found, further comment can be made.

SANITATION

The method by which BRI dispenses food though a belt feeder is a serious concern with regards to sanitation and food safety.

Clients such as [redacted] earned their food based on their behavior. The food that was earned was dispensed along a conveyor belt that had portions of the meal on it. At issue here is the safety of food items stored in or on a conveyor belt for extended periods of time. When food is allowed to sit out, the two critical components of microorganism growth come together; time and temperature.

Sanitation regulations call for food to be cooked to an internal temperature to kill foodbourne pathogens (varies with the type of food) and maintained for service at 140 degrees or higher for hot foods. Foods served cold must be served and maintained at a temperature not exceeding 40 degrees.

Therefore, foods being maintained at room temperature in a beltfeeder do not meet regulations regarding proper food time and temperature. When those foods sit at room temperature for more than 45 minutes to an hour, optimal conditions for food microorganism growth occur.

There exists a wide variety of foodbourne pathogens. They cause a variety of highly unpleasant side effects, and some can lead to death, especially in a person whose health is already compromised in some way. Therefore, it is critical that food safety regulations be followed at all times. The nutritionist wrote a memo regarding this issue on October 29, 1990. These regulations are still not being followed, to my knowledge.

I regard a number of the practices that BRI engaged in regarding the nutritional well being of [redacted] with grave misgivings. In light of the information brought forth in this report, it is my professional opinion that a review of the way BRI uses food as a behavior modifier, by Registered Dietitians and Physicians, be undertaken to ensure the nutritional well being of BRI's clients. I also feel that a dietitian/nutritionist that is there 3 hours a week would not have sufficient time to thoroughly follow such high nutritional risk clients as those that are on the Specialized Food Program.