U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

Registered Mail
Return Receipt Requested

JUL 31 1989

Honorable James Thompson
Governor
State of Illinois
State Capitol Building
Springfield, Illinois 62706

Re: Notice of Findings Regarding the W. A. Howe Developmental Center, 42 U.S.C. Section 1997b(a)(1)

Dear Governor Thompson:

By letter dated April 18, 1986, we informed you that, pursuant to the Civil Rights of Institutionalized Persons Act ("the Act"), 42 U.S.C. Section 1997, the Civil Rights Division of the United States Department of Justice was commencing an investigation into conditions at the W. A. Howe Developmental Center ("Howe"), Tinley Park, Illinois. On May 19, 1988, we provided you with an interim report regarding the status of this investigation. As specified in the Act, we are now writing to inform you that further review confirms that unconstitutional conditions exist at Howe, and also to advise you of the minimum measures we believe are required to be taken by the State in order to remedy those conditions.

Our investigation consisted, first, of several comprehensive tours of Howe by independent experts, most recently between February 15 and 17, 1989. The experts observed conditions in all the residential buildings at Howe at various times of the day, formally and informally interviewed administrators, staff and residents, and examined a variety of records. Further, we conducted interviews with members of advocacy and consumer groups and other persons with responsibilities for the welfare of residents in Illinois developmental centers. Finally, we gathered and analyzed extensive documentation related to Howe, which included: a variety of policies and procedures governing the operation of Howe; information related to Howe's staffing patterns; minutes from Howe's Committees; police reports; abuse investigation reports (available for inspection only); mortality reviews and list of deaths; monthly injury reports; restraint logs; lists of patients on medication; logs of patients placed in

"quiet training" rooms; and a sampling of residents' records. We also have reviewed the Statement of Deficiencies and Plan of Correction resulting from a survey conducted by the Health Care Financing Administration in March 1988 and other documents related thereto. During our investigation we were treated graciously by Howe administration and staff, and attorneys from the Department of Mental Health and Developmental Disabilities.

Based upon our extensive investigation, we believe that conditions exist at Howe which deprive residents of their constitutional rights. The United States Supreme Court has clearly stated that institutionalized mentally retarded persons have a constitutional right to adequate medical care, reasonable safety, and such training as an appropriate professional would consider reasonable to ensure safety and freedom from undue bodily restraint. Youngberg v. Romeo, 457 U.S. 307, 324 (1982).

Set forth below are our findings and recommendations. These findings and recommendations relate to the State subjecting residents of Howe to conditions that violate their constitutional rights, including conditions that seriously threaten the health and safety of Howe residents. These unconstitutional conditions include:

1. Failure to provide sufficient training to residents to avoid undue risks to their personal safety and unreasonable use of bodily restraints.

2. Failure to provide adequate medical care.

3. Failure to provide sufficient numbers of appropriately trained staff to render professional judgments regarding necessary care, training, medical treatment, and to implement such professional judgments.

4. Failure to adequately protect residents from physical injury.

5. Failure to keep and maintain such records as will allow staff to render professional judgments regarding care and treatment of residents.

The facts supporting our conclusions include the following:

Inadequate Training Programs

Howe fails to provide professionally designed and implemented training programs sufficient to ensure that residents are not subjected to unreasonable risks to their personal safety and undue bodily restraint. At the time of the most recent tour, there were five Masters level psychologists working at the facility with 721 residents, resulting in a ratio of 1:144. Our

consultant regarded this ratio as inadequate to serve the needs of the Howe population, particularly since many of the Howe residents are severely disabled, exhibit severe and sometimes dangerous behavior, and live in close proximity to each other. Indeed, our consultant found the number of treatment staff to be so inadequate as to place residents at extreme risk of injury. Several of the Howe staff psychologists agreed that the psychology staff is not adequate. They stated that there were insufficient numbers of their profession to provide professionally designed training programs for residents, including residents exhibiting severe and dangerous behavior.

As a result of an inadequate number of qualified psychologists, available staff rely on the same or similar "stock" behavioral programs for residents irrespective of the individual needs of those residents. This reliance constitutes a substantial departure from accepted professional judgment and places residents at great risk of harm. Our consultant concluded that the failure to professionally evaluate resident need and individualize training programs ostensibly designed to reduce or eliminate aggressive, self-injurious, and other dangerous behaviors will, however inadvertently, produce worse behavior. To control resident behavior, in lieu of professionally designed training programs, staff resort to chemical and physical restraints -- in violation of the constitutional rights of Howe's residents. Indeed, when physical restraints are employed, including use of time out, such procedures are not consistently monitored and evaluated by qualified professional staff.

To the extent "training programs" have been developed, such "programs" are not consistently implemented by direct care staff assigned to do so. Some staff who are responsible for residents who exhibit self-injurious behavior did not know the specific training programs developed for those residents. In this regard, records, including behavior management plans, were locked and unavailable to staff in some units. Our consultant found that data ostensibly resulting from implementation of behavior programs is not recorded contemporaneously with the observed behavior and are not otherwise properly maintained. Such data are not regarded as reliable either by our consultant or Howe psychology staff, and, consequently, are not an adequate basis on which professional decisions can be based. This is due, in part, to the inadequate level of direct care staffing in the units and other factors including the lack of appropriately trained direct care staff.

In sum, activities at Howe characterized by Howe staff to constitute "training programs" represent substantial departures from accepted professional judgment. Regrettably, our consultant concluded that these activities may expose residents to undue risks to their personal safety.

Inadequate Medical Care

Howe does not have adequate psychiatric, nursing, physical therapy, occupational therapy and other specialized medical services to adequately meet the needs of its residents. The absence of necessary staff results in inadequate medical care.

An estimated 15 per cent of the residents at Howe are receiving neuroleptic medication; 24 per cent are receiving psychotropic medication, and many are receiving anticonvulsant medication. Many residents are on multiple psychotropic medications. Such drugs, when prescribed and used without the exercise of continuing clinical medical judgment, can cause irreparable physical harm. Notwithstanding the need for close supervision and monitoring of such drugs by a psychiatrist, a psychiatrist is available at Howe only four hours each week. Our consultant found such psychiatric coverage to be "grossly inadequate."

The number of registered nurses (RNs) available to provide necessary care to Howe's residents is likewise inadequate. From 5:00 p.m. to 11:00 p.m., no RN is on duty. From 11:00 p.m. to 7:00 a.m., one RN is responsible for all medical care for all 720 residents at the facility. This means that one nurse must handle all medical emergencies, treat injuries as they occur, and maintain medical surveillance of residents with complex medical needs. The number of RNs available at Howe is grossly inadequate and exposes residents to unreasonable risks to their personal safety.

No orthopedist is available as a consultant to Howe on a regular basis. Given that approximately 1/4 to 1/3 of individuals with developmental disabilities and mental retardation have orthopedic deformities and that Howe has a unit specifically for the care of individuals with severe multiple handicapping conditions predominantly of a musculo-skeltal nature, this is inadequate. The lack of adequate orthopedic consultation has led to a failure to provide treatment where medically indicated, to a failure to prevent progression of deformities, and to needless suffering on the part of residents. Moreover, the physical and occupational therapy staff is simply inadequate to serve the large number of residents with orthopedic deformities.

A neurologist is available at Howe for only four hours each month. Such neurological consultation is not adequate to serve the needs of the approximately 240 residents with serious seizure disorders on multiple seizure medications.

While our consultant found the number of physicians to be adequate, records indicated that they are not available to

render professional medical judgments at critical junctures in the delivery of medical care at the facility. None is present at the facility from 11:00 p.m. to 8:30 a.m. Our consultant concluded that the absence of physician coverage during this time places residents at risk. Such risk is exacerbated by the absence of adequate RN coverage. In addition, our consultant found inadequate involvement by physicians in resident medical care even when they were available at the facility.

Due to the lack of adequate medical supervision of patients, early signs of illness and disease go undetected and/or untreated. For example, staff at Howe refer residents with scoliosis to an orthopedist only after the scoliosis becomes severe. Thus, the resident's condition is allowed to deteriorate without any attempt at prevention or treatment.

Our consultant physician found that progress notes do not consistently reflect the resident's condition, nor reflect the results of important laboratory tests or medical specialty reports. Moreover, an appropriate and current medical problems list was missing from the medical records reviewed. Our consultant physician also found that physicians' annual reviews are significantly incomplete. The absence of critical information in the medical charts of Howe residents subjects them to an increased risk of harm from inappropriate treatment.

In addition, psychotropic medication appears to be over used and misused at Howe. Our consultant physician found these drugs are sometimes prescribed at Howe without any justification being noted in the record and that physicians do not adequately assess the continued need for such medications. Our consultant psychologist likewise found that the resident records disclose little or no specific evidence that there was consideration of all salient factors of an individual case before the medication was prescribed. Instances were found where residents failed to exhibit significant episodes of maladaptive behavior but their medication dosages were maintained nonetheless. Records examined failed to document justification for the maintenance or alteration of dosages. Moreover, to the extent the underlying behavioral documentation is unreliable, a fact our consultant psychologist found at Howe, residents are placed at clear risk of significant side effects of medication, failures in treatment, and maintenance of chemical regimens which may be unnecessary and expose residents to unreasonable risks to their personal safety.

Finally, our physician consultant found emergency medical services inadequate. Records indicate that emergency equipment is not fully operational on a consistent basis or, in some cases, available at all. The deaths of two residents transferred by Howe to community hospital for emergency medical care calls into question the viability of the state's current procedures for the provision of emergency and acute medical care for residents.

An emergency medical care system which fails to make timely transfers, ensure continuity of care, and fails to provide necessary medical information regarding the referred patients -- with death resulting -- is clearly inadequate.

Inadequate Numbers of and Insufficiently Trained Direct Care Staff

Our consultant concluded that inadequate numbers of staff, lack of properly trained staff, and inadequate oversight has led directly to situations which placed residents in physical danger, and in which actual harm has been inflicted. The physical configuration of the living areas is such that the two direct care staff assigned to each living unit cannot keep all residents in sight. Given the aggressive behavior of some of these residents and the fact that many exits are not alarmed to alert staff if a resident leaves, the lack of sufficient staff to supervise residents results in undue risk to their safety. Further, most residents require assistance in bathing and dressing and tending to other personal needs. The two direct care staff assigned to the 10 residents of each living unit are inadequate to provide these essential services and provide necessary training as well, particularly where, as here, some direct care staff are performing routine housekeeping functions. The failure to ensure adequate numbers of direct care staff subjects residents to undue risk of harm from injury.

The gravity of this situation is conveyed by the incidents of injury at Howe. Based on the information available to us, we calculate the average number of injuries per month at Howe increased dramatically from 1986 through 1988. There was a five per cent increase from calendar 1986 to calendar 1987 (i.e., from an average of 367 to 387 injuries per month), and an increase of another 14 per cent from 1987 to 1988 (i.e., from 387 to 442 injuries per month). That is an overall increase of 20 per cent in just two years (i.e., from an average of 367 to 442 per month). This increase is all the more substantial when one considers that during this time the resident population at Howe declined.

In addition to the increasing number of injuries at Howe, the nature of several specific serious incidents which have occurred illustrate the fact that staff at Howe do not protect residents from harm. For example, in March 1988 a resident was found dead on the floor of her room at 6:15 a.m., with signs of lividity indicating she has been dead for some time. It was subsequently determined that direct care staff failed to perform routine bed checks during the night. In the same month, another resident was found hanging over the side of her bed, strangled to death by a posey bed restraint which had been incorrectly applied. An autopsy disclosed that this resident's sternum had been broken during attempts at cardiopulmonary resuscitation

(CPR). The staff person who had performed chest compression on the resident had received no CPR training after she was hired in 1982. A subsequent investigation disclosed that staff training in the use of the posey device had concentrated on wheelchair application and neglected bed application entirely. In another incident occurring shortly before our tour, a resident ran from the front door of her living unit to the street and was killed by a passing automobile. At the time the resident left her living unit, one of the two direct care staff assigned to supervise her and other residents was at lunch, and the other staff person was writing in a log book. In sum, direct care staff is insufficient both in numbers and qualifications to protect residents from unreasonable risks to their personal safety.

Minimally Necessary Remedies

The administration and staff at Howe appear committed to providing residents with appropriate care in a safe environment. However, the aforementioned subjects Howe residents to egregious or flagrant conditions that deprive them of their constitutional rights pursuant to a pattern or practice of resistance to the full enjoyment of these rights. To rectify the deficiencies at Howe, and ensure that constitutionally adequate conditions are maintained thereafter, we propose to enter into an agreement with the State of Illinois which shall be entered as an order of a Federal Court and which shall provide, at a minimum, that Howe shall implement the following remedies:

1) Professionally design and implement training programs sufficient to eliminate unreasonable risks to personal safety and undue bodily restraint. Such procedures should include improvements in the current tracking and recordkeeping systems to monitor the effectiveness of behavior management programs and allow programs to be re-evaluated and revised, as appropriate;

2) Increase professional and direct care staff necessary to afford adequate medical care, to provide that degree of training necessary to meet constitutional standards, and substantially reduce the high incidence of physical injuries at Howe;

3) Improve drug practices to ensure monitoring by qualified professionals consistent with exercise of professional judgment;

4) Improve and expand training programs and opportunities for professional and direct care staff to ensure the exercise of professional judgment with respect to care and training of residents;

5) Improve recordkeeping procedures to ensure necessary information is available to enable professionals to make professional judgments regarding resident care and training.

Information about federal financial assistance which may be available to assist with the remedial process can be obtained by contacting Mr. Hiroshi Kanno, Acting Director, Region V, Department of Health and Human Services at (312) 353-5132 and from the Department of Education by contacting the individuals listed in the enclosed information guide.

Our attorneys will be contacting counsel for the Illinois Department of Mental Health and Developmental Disabilities shortly to arrange a meeting to discuss this matter in greater detail. In the meantime, should you or your staff have any questions regarding this matter, please feel free to call Arthur E. Peabody, Jr., Chief, Special Litigation Section at (202) 272-6060. To date, we have been able to conduct this investigation in the spirit of cooperation intended by the Civil Rights of Institutionalized Persons Act, and look forward to continuing to work in the same manner with state officials in that spirit toward an amicable resolution of this matter.

Sincerely,

James P. Turner
Acting Assistant Attorney General
Civil Rights Division

Enclosure

cc: Neil F. Hartigan, Esq.
Attorney General

Ann Kiley
Director, Illinois Department of Mental Health and Developmental Disabilities

Kathleen A. Muniz
Superintendent, Howe Developmental Center

Delilah Brummet, Esq.
Chief Counsel, Illinois Department of Mental Health and Developmental Disabilities

Anton R. Valukas
United States Attorney