



U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

DEC 3 1992

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CRIPA Investigation



MR-CA-002-001

The Honorable Pete Wilson
Governor of the State of California
Office of the Governor
State Capital Building
First Floor
Sacramento, California 95814

Re: Findings Letter Regarding Agnews Developmental
Center, San Jose, California

Dear Governor Wilson:

I am writing to inform you of the findings of our investigation of the Agnews Developmental Center ("Agnews") in San Jose, California, pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997 et seq. We identified serious deficiencies regarding the provision of resident care that deprive the residents of their constitutional rights. Set forth below are our findings of unconstitutional conditions and the necessary remedial measures to correct these violations. The Attachment to this letter includes the facts supporting our determination of unconstitutional conditions.

Unconstitutional Conditions at Agnews

Based on our extensive investigation, we conclude that the following conditions at Agnews deprive residents of their constitutional right to safe conditions, adequate medical care, and such training as an appropriate professional would consider reasonable to ensure their safety and freedom from undue bodily and chemical restraints. See Youngberg v. Romeo, 457 U.S. 307, 324 (1982).

1. Inadequate protection of Agnews residents from injury and undue risks of harm;

2. Inadequate development, implementation, and monitoring of resident training programs, including behavior programs;

3. Excessive, unjustified use of bodily and chemical restraints in lieu of training programs;

4. Inadequate medical care, including mental health services;

5. Failure to provide essential physical and occupational therapy services; and

6. Failure to provide competent and qualified staff which contributes significantly to the unconstitutional conditions at Agnews.

The facts supporting our findings regarding these constitutional violations are set forth in the Attachment accompanying this letter.

Minimal Remedies to Correct the Unconstitutional Conditions

In order to eliminate the egregious or flagrant conditions that deprive Agnews residents of their constitutional rights, the following measures, at a minimum, are necessary:

1. Immediate steps must be taken to provide for increased safety of residents and provision of their basic needs. Such steps should include increased supervision of residents by direct care staff, enhanced training to ensure staff can meet their responsibilities to afford basic hygiene measures and to intervene with residents exhibiting aggressive behavior, and the strengthening of resources for the care of physically handicapped residents.

2. A comprehensive system to identify, investigate, and, if necessary, implement remedial measures for abuse of residents must be developed.

3. All residents must be evaluated by a professionally constituted inter-disciplinary team to determine their individual need for care, treatment, and training. Based upon such evaluations, professionals must develop for each resident an individualized training program sufficient to ensure their personal safety, reduce or eliminate the use of physical and chemical restraints, and prevent physical deterioration. Such programs should include behavior modification programs, training in the development of self-care skills, and such other programs a professional may deem necessary to meet resident needs.

4. The use of undue physical and chemical restraints to control resident behavior in lieu of professionally developed training programs must be eliminated.

5. Medical care, including the provision of mental health services, must be significantly improved. Steps should be taken to ensure that the facility provides adequate routine, chronic, and acute health care to its residents, including timely diagnosis, specialty consultations and follow-up treatment. Policies and procedures for the use and monitoring of the use of psychotropic medications must be reviewed and modified, as necessary, to ensure compliance with generally accepted standards for the use of such drugs.

6. All physically handicapped or medically fragile residents must be evaluated by qualified professionals to ensure that their basic health care needs are addressed, including the provision of such therapies a qualified professional may deem necessary to ensure safe feeding, the prevention of muscle atrophy, physical degeneration, and inappropriate body growth and deformity.

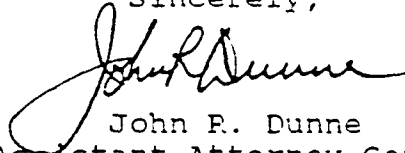
7. Enhanced professional resources are required at Agnews. There are significant staffing deficiencies at the facility adversely affecting resident care. Such deficiencies are particularly acute in the areas of medical care, including mental health services and physical and occupational therapy, and in those categories of staff responsible for the supervision and basic care of residents.

We appreciate the cooperation extended to us thus far during our CRIPA investigation by the Director and the staff of Agnews Developmental Center, officials of the California Department of Developmental Services, and counsel for the State. We hope that the cooperative spirit will continue. You may wish to contact the regional offices of the United States Departments of Health and Human Services and Education to ensure that state and local officials have taken full advantage of any available federal financial assistance which may be available to assist in the correction of these deficiencies. If we can assist you in this regard, please contact us.

My staff will contact legal counsel for the California Department of Developmental Services shortly to discuss this matter in greater detail. In the meantime, should you or your staff have any questions regarding this matter, please contact Arthur E. Feabody, Jr., Chief, Special Litigation Section, at (202) 514-6255.

I hope and trust that we will be able to resolve this matter in an amicable and reasonable manner.

Sincerely,



John R. Dunne
Assistant Attorney General
Civil Rights Division

Enclosure

cc: The Honorable Daniel E. Lungren
Attorney General
State of California

The Honorable Ralph Johnson
Assistant Attorney General
State of California

Michael Mount, Esq.
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Mr. Santi J. Rogers
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Mr. Dennis Admunson
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Mr. Anthony Tyrone
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John A. Mendez, Esq.
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Northern District of California

ATTACHMENT

Facts Supporting Findings of Constitutional Violations at Agnews Developmental Center

In response to widely reported allegations of abuse and inadequate care and treatment of residents, the United States Department of Justice investigated Agnews Development Center ("Agnews") on October 5-9, 1992. The investigation consisted of a tour of all facilities and programs at Agnews by three consultants - a physician, a psychologist, and a physical therapist - accompanied by attorneys from the Department. The tour included: 1) observing conditions at the facility; 2) interviewing administrators and staff; 3) reviewing a large number of resident records; and 4) examining and analyzing numerous other documents, including facility incident reports and analyses, committee meeting minutes, mortality reviews, staffing patterns, and various policies and procedures.

The facts disclosed during the course of the investigation that support the Department's findings of unconstitutional conditions at Agnews are set forth below.

I. Agnews is Unable to Provide for the Reasonable Safety of its Residents and for Training Programs to Ensure Freedom from Undue Bodily Restraints

A. Failure to Provide for Reasonable Safety and to Protect Residents from Harm, Including Neglect and Abuse

1. Neglect

The care at Agnews falls so substantially below the level of care and training considered appropriate by a qualified professional as to constitute active neglect, *i.e.*, neglect that physically harms residents. This active neglect ranges from gross inattention to residents to the failure to attend to their most basic personal needs. Such neglect exposes residents to significant dangers.

During the investigation, we observed naked residents completely unsupervised running and falling in corridors of various units. Many exhibited highly aggressive behavior. In addition, we observed residents unattended in dayrooms and even in showers. Numerous toilets filled with fecal matter left unflushed were likewise identified during the course of tours of facilities by our consultants. Unflushed toilets present an especially significant risk to residents exhibiting pica behavior, *i.e.*, eating foreign or inedible objects. A review of resident records indicates that residents are subjected to multiple, serious injuries.

As well, numerous residents with severe pica behavior are left unattended in facilities filled with objects which can be easily eaten and swallowed. As a result residents have been subjected to serious injuries and death. One resident swallowed a plastic glove and died. Another resident left unattended swallowed bits and pieces of a sweater, vomited the sweater and required emergency medical treatment. Records indicate that pica behaviors and its associated dangers are a significant problem at Agnews.

Personal hygiene needs and physical care of residents is grossly deficient. A nurse consultant for the California Department of Developmental Services who accompanied us on our tours on behalf of the State recently submitted a report to Agnews in which she noted:

Clients are unkept, hair not combed and wearing clothing stained with food. Clients were fed too fast and fluids were poured into clients [sic] mouths until they coughed and swallowed. Clients and residence smelled of urine and feces. . . . It appears that staff have not been held accountable for these conditions. . . .

Our consultants confirmed these observations.

Care of physically handicapped residents is especially deficient. In addition to inadequate feeding practices, our consultants saw resident after resident whose legs had lost all muscle tone and whose hip, knee and ankle joints had become permanently fixed or cemented in place in a deformed frog-leg or windswept position due to months and even years of inactivity. Other gross abnormalities due to neglect and the absence of care were identified.

2. Abuse

Abuse of residents by staff is a significant problem at Agnews. With candor, administrators at the facility confirmed to us that staff abuse of residents is a serious problem at the facility and remedial steps are being initiated. Records provided by Agnews indicate that staff has abused residents on at least 16 separate occasions this year alone. The most flagrant example of staff abuse occurred earlier this year when a psychiatric technician beat and stabbed a resident to death. Our investigation confirms this problem and indicates that, to date, Agnews has not developed adequate controls to identify and remedy the systemic problem of abuse.

Agnews lacks an effective system of reporting, tracking and investigating abuse. Agnews currently has only one special

investigator for the entire facility of approximately 1000 residents. Also, staff do not adequately report incidents of injury and abuse. The definition of what constitutes a reportable injury is so vague that staff are unable to precisely determine and, therefore, record such incidents. Furthermore, due to insufficient numbers of adequately trained staff, staff are often left alone to control large groups of residents. Consequently, staff who may cause abuse are the ones with total discretion for reporting the abuse. Our consultant found that without a proper system for reporting abuse, the facility will be unable to effectively identify and discipline abusive staff or implement other necessary remedial measures. In sum, Agnews lacks an internal control system sufficient to identify and combat abuse of residents by staff.

B. Inadequate Assessment, Development, Implementation, and Monitoring of Training Programs

Agnews has a large number of residents with aggressive, self-injurious, and pica behaviors who need appropriate behavioral training programs. Our consultant psychologist found that Agnews residents are being subjected to actual harm and unreasonable risk of injury due to major deficiencies in the development and implementation of training programs.

First, Agnews is failing to adequately assess the needs of residents, including their need for behavior programs. Resident records consistently reflect assessments which constitute substantial departures from generally accepted professional standards for assessments. Absent an adequate assessment of need, the development of an appropriate training program is not possible.

Second, individual treatment plans (ITP's) are not properly developed. For example, our consultant noted that records consistently fail to indicate in specific terms the behavior to be changed or modified by the training program. As a result of this deficiency, effective monitoring of the program is not possible and modifications, if necessary, cannot be identified. More importantly, the resident does not receive the training necessary to ameliorate or eliminate the anti-social or dangerous conduct being exhibited. As a result, residents are subjected to various control devices, including physical restraint, to manage their behavior.

Third, staff are not qualified and have not been adequately trained to both develop and implement training programs. Lack of competence and expertise contributes significantly to the staff's inadequate behavioral assessments, poor development of ITP's, unawareness of behavior plans, and limited understanding of behavior management in general.

Finally, our consultant found that evaluation of client progress in behavioral training and skill acquisition programs is not consistent with professional standards. Every psychologist interviewed stated that the information collected with respect to the implementation of individual resident behavior programs is unreliable and does not meet professional standards.

The absence of professionally based training programs for residents has contributed to the multiple injuries suffered by residents and to other dangerous conditions at the facility. For example, based on an Agnews internal count of incidents alone, in the months of July, August and September of this year, clients at Agnews suffered over 320 injuries. Many of these injuries resulted from acts of aggression by other residents. Residents have been bitten, pushed, slapped, hit, kicked, and choked by their inappropriately aggressive peers who do not have adequate training programs. The injuries consist of fractures, burns, abrasions, and deep lacerations that must be sutured.

Furthermore, residents have repeatedly injured themselves through their own maladaptive behavior. Many clients bang their heads on walls, others slap and hit themselves, and a few clients have caused themselves to bleed by continually digging at their rectum. Significant numbers of "accidental injuries" and injuries of "unknown origin" have also been recorded. These injuries indicate a significant lack of active intervention by staff, the absence of training programs, as well as grossly deficient supervision and monitoring of the residents.

C. Failure to Ensure Resident Freedom from Undue Bodily and Chemical Restraints

Agnews residents suffer an unreasonable amount of physical and chemical restraint without adequate justification. Our consultant found that staff use excessive bodily and chemical restraints in lieu of behavior training programs and for their own convenience to control the residents.

In the absence of training programs or skills necessary to address aggressive behaviors exhibited by residents, staff routinely resort to highly restrictive physical restraints. In addition, our consultant noted numerous instances where residents are restrained for extended periods of time without any justification in their records to support the continued need for restraints. Furthermore, our consultant noted that Agnews engages in widespread and extensive use of medication to control maladaptive behavior in the absence of training programs and other generally accepted procedures. Such undue reliance on chemical restraint subjects residents to the harmful side-effects of psychotropic medication.

In sum, our investigation revealed that staff rely on both physical and chemical restraints to control residents in lieu of professionally developed training programs.

II. Agnews Fails to Provide Adequate Medical Care

A. Inadequate Medical and Nursing Care

Based on our review of resident records at Agnews, significant deficiencies exist in Agnews' responses to acute and chronic resident illnesses. The need for timely and appropriate medical attention is especially critical at Agnews since a large percentage of the resident population is multiply handicapped and medically fragile.

Our review of Agnews documents demonstrates that the emergency medical response system at Agnews is seriously flawed. Agnews' own Emergency Response Committee has identified three recent emergency care incidents where significant problems occurred in staff responses to medical emergencies. In one such instance, when responding to a resident who was suffering a cardiac arrest, the unit staff was unfamiliar with the cardiac tray on the crash cart and could not locate needed medications. In another instance, staff was confused whether the local fire department or county paramedics should be called to the emergency. This confusion resulted in undue delay in getting medical care to the scene of the emergency. In the third instance, our consultant noted that unit staff failed to record a resident's vital signs. Documents on this incident also indicated that the oxygen tank needed for the resident was empty. It is our consultant physician's opinion that these deficiencies severely impair the facility's ability to respond to serious medical emergencies. As such, they require immediate correction.^{1/}

Significant deficiencies also exist in the delivery of routine and chronic medical care. Our consultant physician noted that medical evaluations of Agnews residents are often incomplete and do not contain adequate discussion of a resident's diagnosis or adequate treatment plans. We also identified instances of inordinate delays in diagnosing and responding to serious resident illnesses. For example, we found instances where Agnews physicians delayed ordering necessary diagnostic tests, particularly x-rays, in cases where clients had developed

^{1/} It is also problematic that the facility's emergency response team is located on the West campus of the facility, over two miles from the East campus where the vast majority of clients reside. Response time is compromised since the emergency team must drive over busy public roads to reach the East campus.

pneumonia. Due, in part, to these delays, our medical consultant identified cases where physicians did not diagnose or appropriately treat pneumonia cases in a timely manner. Such a deficiency is especially critical at Agnews given the large percentage of residents exposed to the risk of pneumonia due to their fragile medical condition.

Physicians are also failing to order x-rays following behavior-related events that clearly indicate the need for an x-ray. For example, we reviewed the chart of one resident who had vomited the collar of a sweatshirt. However, no x-ray was ordered to determine if the resident had ingested other parts of the shirt. The failure to order x-rays in such instances is a serious deficiency at Agnews in light of the number of residents with severe pica behavior.

Significant delays occur in obtaining needed consultations with various medical specialists, particularly pulmonary consultations. Again, this is a serious and harmful deficiency given the large number of pneumonia cases occurring among the Agnews resident population. Significant delays also occur in obtaining neurology consults. Because a large percentage of the Agnews resident population is on anticonvulsant medication, delayed neurology consults is a harmful deficiency. Numerous cases exist where an audiologist recommended an ENT consult, but many months passed before a consult was obtained. There are also insufficient gastrointestinal and respiratory consults. Given the high degree of medical involvement of many residents at Agnews, the failure to provide timely consultations with medical specialists is a major deficiency that seriously jeopardizes the health of residents.

Our consultant physician also found numerous cases where Agnews is not adequately monitoring the health status of residents. For instance, resident records show numerous cases where residents either lose or gain significant amounts of weight without adequate consideration of the causes of the weight fluctuation or adequate intervention to prevent further weight loss or gain. Our consultant also identified cases where the serious illness of a resident had not been detected by staff. We also identified recurrent patterns of inadequate monitoring of resident temperature levels, contractures, seizure activity, fluid intake and output and immunization status.

Agnews also experiences significant problems in obtaining treatment reports from outside hospitals when Agnews residents are transferred to acute care. Often these residents will return to Agnews without documentation of treatment or instructions regarding their continuing care. The absence of such information makes it difficult, if not impossible, for Agnews to provide adequate follow-up medical care.

Agnews also lacks a sufficient mechanism for assuring the quality of care of its medical services. For example, the facility has established various committees to review the quality of medical-related services. These committees, however, meet infrequently and, according to our medical consultant's review of records, deal superficially with the issues presented. Given the problems that exist in the medical care delivery system at Agnews, a thorough quality assurance system is necessary.

B. Inadequate Mental Health Services

Mental health services at Agnews are grossly inadequate. At the time of our tours, only one full-time psychiatrist was providing psychiatric care. This psychiatrist carries a caseload of 80 patients. However, there are approximately 250 residents at Agnews on psychotropic medications. Thus, a majority of the residents on psychotropic medications at Agnews are simply not provided mental health evaluations or supervision despite being exposed to the harmful risks associated with using these powerful medications. No data exists in resident records indicating that medication reviews are being performed to determine the continued need of the medication or whether the medication is detrimentally affecting the resident.

Adding to the mental health care deficiencies at Agnews is the facility's lack of a standardized system for monitoring the side effects of psychotropic medications. A number of residents at Agnews are suffering from tardive dyskinesia, an irreversible and debilitating side effect of the long-term use of psychotropic medications. Given that many Agnews residents are on psychotropic medication regimens for extended periods of time, the absence of an adequate side-effect monitoring system represents a substantial departure from accepted professional judgment and exposes residents to the risk of harm associated with using such medications.

Our consultant also noted numerous instances where residents are maintained on anticonvulsant medications in the absence of recorded seizure activity to justify the use of the medication. At least one resident whose chart we reviewed was on two different anticonvulsants, but had no recent recorded seizures.

In sum, significant deficiencies exist in Agnews' ability to provide routine, chronic and acute medical care to its residents.

C. Failure to Provide Essential Physical and Occupational Therapy Services

After extensive review of the physical and occupational therapy services offered at Agnews, our consultant physical therapist concluded that Agnews fails to adequately provide these services and that such failure constitutes a serious and harmful

deficiency in the residents' medical care. Currently, there is no physical therapist on staff and only three full-time and nine part-time occupational therapists at Agnews. For a facility with close to one thousand residents, our consultant considers such a limited staff to be grossly inadequate to provide the necessary therapy services to this large and needy population.

The failure to provide necessary physical and occupational therapy services results in contractures, muscle atrophy, irreversible physical degeneration, inappropriate body growth, and deformity. Such problems, in turn, subject residents to eating, digestion, urinary tract, and other general medical problems, e.g., respiratory difficulties due to scoliosis.

Despite the need for active physical therapy programs, Agnews is failing to provide such programs. No physical therapy assessment is performed on residents and there are no individualized physical therapy treatment programs. Only a handful of residents receive active occupational therapy treatment. Most residents receive absolutely no occupational therapy. Instead of receiving therapy, most residents sit in their chairs or carts most of the day in idleness. Moreover, these physically handicapped residents are not positioned properly. Absent movement, they suffer serious physical deterioration and other threats to their health.

Furthermore, there is no physical management care plan in the residents' records to instruct the direct care staff on how to appropriately handle a resident's individualized positioning and transfer needs. Without this type of individualized instruction, injuries often result because direct care staff improperly position and transfer the residents.

Our consultant likewise concluded that the use of adaptive equipment at Agnews is not in keeping with generally accepted professional standards. Inappropriate use of such equipment jeopardizes the health and safety of the residents. Ill-fitting adaptive equipment does not provide adequate support, thereby increasing the risk of accidental injury and physical deterioration.

The lack of adequate therapy services coupled with improper feeding techniques has produced a number of medical complications at Agnews. Our consultant found that aspiration has resulted from and will continue to occur due to the common practice at Agnews of feeding the residents while they are reclined in their carts. The consultant also found that residents with swallowing difficulties are placed on tube feeders without any attempt to improve their swallowing. This does not solve the aspiration problem, but creates new problems of loss of muscle strength in the mouth, retraction of the jaw and the development of an

overbite, all of which decreases a resident's ability to chew, hold fluids, cough or gag when necessary.

In sum, Agnews fails to provide physical and occupational therapy services and adequate staff to render appropriate and necessary care to address the physical and occupational therapy needs of the residents of Agnews.