U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

JUN 29 1995

The Honorable Edwin W. Edwards
Governor of Louisiana
State Capitol
P.O. Box 94004
Baton Rouge, LA 70804-9004

Re: Pinecrest Developmental Center

Dear Governor Edwards:

On October 12, 1994, we notified you, pursuant to the Civil Rights of Institutionalized Persons Act, 42 U.S.C. § 1997, of our intent to investigate conditions at the Pinecrest Developmental Center ("Pinecrest") in Pineville, Louisiana. From January 9-13, 1995, we conducted our investigative tour of the facility accompanied by three expert consultants: Nirbhay N. Singh, Ph.D., a developmental psychologist, Maureen A. Fee, M.D., a developmental pediatrician, and Victoria M. Therriault, MS, MN, ARNP-C, a developmental nurse practitioner.

In investigating Pinecrest, our intent was to ensure that the constitutional and statutory rights of the residents were being protected. All residents of state operated institutional facilities have a fundamental Fourteenth Amendment due process right to adequate food, clothing, shelter, medical care, reasonably safe conditions, and training. Youngberg v. Romeo, 457 U.S. 307 (1982). As such, this right entitles residents to such care and training as to protect each resident's liberty interests and permit each resident an opportunity to function as independently as is reasonably possible. Individuals with disabilities have a right to programs to teach adaptive behaviors, self-help skills, communication, social skills, and skills necessary to enhance independence. See, e.g., United States v. Tennessee, No. 92-2062, slip. op. (W.D. Tenn. Feb. 17, 1994); Thomas S. by Brooks v. Flaherty, 699 F. Supp. 1178 (W.D.N.C. 1988), aff'd, 902 F.2d 250 (4th Cir.), cert. denied, 498 U.S. 951 (1990). In addition, individuals with developmental disabilities must be provided services in community-based programs where appropriate. See, e.g., Title II of the Americans

with Disabilities Act ("ADA"), 42 U.S.C. §§ 12132 et seq. (and implementing regulations, 28 C.F.R. 35.130(b)(1), and 28 C.F.R. 35.130(d)); Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §§ 794 et seq. and the regulations promulgated pursuant thereto. Further, school-aged residents are entitled to an appropriate education in accordance with the Individuals with Disabilities Education Act ("IDEA"), 20 U.S.C. §§ 1400 et seq.

Consistent with statutory requirements, we are now writing to inform you of our findings and necessary remedial measures. Throughout our visit, the Pinecrest administrators and professional and direct care staff were all quite frank in acknowledging that many service areas were insufficient and needed remedial attention. As a result, it should come as no surprise that during our tour, we found numerous conditions that violate the constitutional and statutory rights of the Pinecrest residents. The facts disclosed during the course of our investigation supporting our findings of unlawful and unconstitutional conditions at Pinecrest are set forth below.

As a preliminary matter, however, we would like to stress that we appreciated the cooperation and courtesy shown us by everyone from the Louisiana Department of Health and Hospitals ("DHH") and by the administrators and staff at Pinecrest. Mr. Charles Castille, Deputy Secretary of DHH, made a special effort to personally meet with us to set a positive and cooperative tone for the tour. We would also like to recognize the diligent and commendable efforts of Mr. Edwin M. Wright, the Pinecrest superintendent, and his dedicated staff. The facility's pre-tour document submission was comprehensive and well organized, reflecting a great deal of hard work and care. While we were at the facility, Mr. Wright and his staff made every effort to ensure that our team had access to whatever additional information we needed. We hope to be able to continue working with the State in such a cooperative atmosphere.

A. PSYCHOLOGY SERVICES SUBSTANTIALLY DEPART FROM ACCEPTED PROFESSIONAL STANDARDS

Our psychology expert found that essential aspects of Pinecrest's psychology services depart substantially from accepted professional standards. Moreover, there is an acute shortage of well trained behavioral psychologists at Pinecrest. There are no licensed psychologists or psychologists with a Ph.D. who have training in behavioral psychology, and the current ratios for the psychologists at Pinecrest are unacceptable, having an acknowledged negative impact on client services.

1. Behavioral programs are inadequate.

The State is failing to provide the residents of Pinecrest with adequate individualized behavioral programming to ensure and protect the Pinecrest residents' safety and liberty interests. 1/

Pinecrest has custody of a large number of residents with serious maladaptive behaviors such as physical and verbal aggression, eating inedible objects (pica), self-injurious behavior, property destruction, non-compliance, temper tantrums and agitation. Behavior problems pose physical and emotional risks to the individual and to other residents. Individuals living in an institution like Pinecrest must be protected from physical injury and psychological harm stemming from behavior problems and must be taught appropriate, useful behaviors to replace maladaptive behaviors.

At Pinecrest, however, many individual residents with maladaptive behaviors have been forced to endure the same ineffective and professionally inadequate behavioral program for years even though they are still engaging in the same harmful behaviors that were initially targeted in the original program. For example, because of Pinecrest's ineffective behavioral treatment interventions, Dorothy L. has suffered with physical and verbal aggression since 1950. Similarly, because Pinecrest has been unsuccessful at treating her, Lucy P. has suffered with self-injurious behavior since 1954. Pinecrest has been unsuccessfully treating Stanley B. for physical aggression since 1987. These are just a few representative examples of this systemic problem.

An individualized behavioral treatment program, devised and implemented according to currently accepted professional practices, can reduce and eliminate these maladaptive behaviors and teach functional alternatives. However, the behavioral treatment programs currently utilized at Pinecrest do not comport with accepted professional standards. Our consultant psychologist found that Pinecrest residents are being subjected to harm, unreasonable risk of injury, and unreasonable restraint

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1/ Because of our investigation, the State has taken a few positive steps to improve psychological services at Pinecrest, including the hiring of a Ph.D. consultant, Dr. Johnny Matson. Dr. Matson has begun working with the staff to alter data collection, revise existing programs, and write new programs for the residents. Nonetheless, as of our visit, none of the new and/or revised programs or data collection systems had yet been implemented. While recognizing hope for the future, this findings letter must necessarily address only those services actually provided to the residents at the time of our visit.

due to major deficiencies in the assessment of residents and in the development, implementation and monitoring of resident behavioral programs. As a result, the State is failing to provide reasonably safe conditions and to ensure freedom from undue restraint of the Pinecrest residents.

2. Training programs are inadequate.

The State is failing to provide the residents with that level of individualized training necessary to enhance functioning, and facilitate their growth, development, and independence. In the absence of such programs, Pinecrest residents do not develop the skills necessary to exercise any degree of independence and they remain totally dependent on staff to meet all their needs.

It is universally accepted in the field today that training programs should not focus on the acquisition of meaningless, rote or otherwise isolated skills, but rather should focus on the acquisition of useful or "functional" skills that have relevance to functioning in society at large. In this way, the new skills that a person with mental retardation learns enable the person to exercise control over the environment and thereby become more independent. However, at Pinecrest the training programs do not meet these basic professional standards. None of the training programs at Pinecrest reviewed by our consultant were adequate to ensure that useful skills were being taught and that such skills were transferrable to living in the community. Moreover, the absence of professional involvement, including psychologists, communication specialists, physical therapists, and occupational therapists, in program areas results in severe limitations in the scope and quality of skills training. Further, Pinecrest's failure to integrate behavior programs and skills training programs results in a non-coordinated approach to teaching. In sum, the deficiencies at Pinecrest in this area deprive residents of their rights to learn useful skills and gain independence.

3. Restraint usage is excessive.

The State is failing to ensure that Pinecrest residents are free from undue or unreasonable restraint. Pinecrest's restrictive practices are not only professionally unacceptable and cause harm, they violate the residents' liberty interests. Because behavioral interventions at Pinecrest are developed largely on the basis of trial and error, attempts at positive approaches have been ineffective, leading to the regular and repeated use of restraints and time out. In fact, over 320 residents are currently listed as on behavioral programs that include some form of restrictive or invasive procedure. These restrictive procedures are neither functionally the least aversive nor the most effective for each individual. As a result, the Pinecrest treatment programs have not produced

socially significant changes in the residents' behavior and ability to function as normally as possible.

Even though some positive, non-aversive components are used in programming at Pinecrest, they are ineffective and are not designed to teach safe and socially acceptable behaviors for the individuals who continue to engage in severe behavior problems, often for years. As a result, unplanned restraints often must be used to compensate. Our consultant concluded and we find that "[t]here is a gross over-use of unplanned physical and mechanical restraints at Pinecrest ... dozens of individuals are in unplanned restraints for hundreds of hours in the absence of effective intervention." In fact, Pinecrest provided us with nearly 500 pages of documented uses of unplanned restraint.

In addition, emergency chemical restraints are regularly and widely used at Pinecrest. Particularly troublesome is the fact that the emergency use of psychotropic medications is increasing even though the number of residents living at the facility has been decreasing. Our consultant concluded and we find that "[t]hese figures indicate that the behavioral and psychopharmacological treatments for the residents at Pinecrest are not very effective and staff have to resort to emergency use of psychotropics to keep the residents' behavior under control." For example, one Pinecrest staff person admitted that ineffective behavioral programming for Nancy L. has led to regular and repeated use of emergency chemical restraint and unplanned physical and mechanical restraint on her. There are a great many other Pinecrest individuals who have been subjected to such repeated emergency or unplanned restraints.

Allowing individuals to engage in high rates of severe problem behaviors that require excessive application of emergency restraints cannot be justified; the use of these restraints should prompt the treatment team to revise the individual's behavioral treatment. Our consultant concluded and we find that, "[a]llowing the individual to engage in high rates of severe problem behaviors that require excessive applications of physical restraints, whether for emergency protective purposes or as a part of a behavior treatment protocol, cannot be justified under any condition. Unplanned restrictive procedures, as well as planned but ineffective restrictive procedures, cause physical, emotional and psychological harm to the residents. These practices cannot be justified and must cease immediately. They certainly substantially depart from generally accepted standards." Such practices violate the residents' liberty interests.

As a final note, we must emphasize that, although in practice, their services departed from what was generally accepted, we found the existing psychology staff to be dedicated, caring and loyal. With proper direction and added expert

support, we believe they can form the nucleus of a restructured and revitalized psychology department at Pinecrest. In large measure, the lack of adequate training of the existing psychology staff has failed them. As our consultant concluded and we find "[t]hey have been misguided by their superiors into doing what is patently wrong and harmful to the residents and, until just recently when the consultant psychologist was hired, they did not have any in-service training in currently accepted methods for the assessment, diagnosis, and treatment of behavior problems or in the writing of skills training programs."

B. PSYCHIATRIC CARE AND SERVICES ARE INADEQUATE AND DO NOT MEET THE NEEDS OF THE RESIDENTS

Dually diagnosed individuals with mental retardation and mental illness are inadequately served at Pinecrest. Currently, the facility has contracted with a part-time psychiatrist for 16 hours per week. However, everyone at the facility, including the consultant psychiatrist, acknowledged that this is not enough time to meet the needs of the many dually diagnosed residents. In fact, Mr. Wright admitted that not every resident who needs to see a psychiatrist gets to see one. Seventy-eight percent of all those residents on psychotropic medications have not had a timely psychiatric consult within the past year. Close to half have been provided with no psychiatric consult at all.

Further, the residents are not receiving any measure of quality psychiatric expertise for their mental illness. The consult psychiatrist admits that he has little formal training treating those with developmental disabilities. It is clear that the Pinecrest staff doctors are not expert enough to meet the residents' psychiatric needs. Moreover, the Pinecrest behavioral data about residents, including environmental and biological information, is inadequate and flawed. The facility's inability to record and track such essential behavioral data and information make providing adequate psychiatric services virtually impossible. In addition, there is almost no integration of behavioral and psychopharmacological treatment.

Pinecrest misuses and overuses psychotropic medication. Multiple use of psychotropic medications or "polypharmacy" is used at Pinecrest because the residents' psychiatric and/or behavior problems are not controlled well enough due to the general lack of expertise, staff and adequate data collection. Some staff admitted to seeing no effective alternative to the use of psychotropic medications to control the problem at hand. This perception underscores deficiencies in Pinecrest's behavior programs. Almost one-third of the residents on psychotropic medication are treated with polypharmacy. A number of residents are receiving three and four psychotropic medications and yet are not receiving any expert consultation from a psychiatrist. Finally, Pinecrest fails to adequately monitor and treat serious

side effects from psychotropic medications. As a result of these significant deficiencies, our consultant concluded and we find "[c]learly, the psychiatric services at Pinecrest are inadequate and substantially depart from generally accepted practice."

C. PINECREST'S INSTITUTIONAL ENVIRONMENT IS OVERLY RESTRICTIVE, NOT FUNCTIONAL, AND FAILS TO MEET THE NEEDS OF THE RESIDENTS

In providing care and services to individuals with developmental disabilities, it is essential to furnish them with an acceptable and responsive environment that ensures safety, and promotes learning and their own social well-being. Such environments are functional and provide a setting for an enhanced quality of life for the individuals. Currently accepted professional standards require that an acceptable and responsive environment is one that is the most integrated with society at large, is stable, safe and engaging, operates to teach and maintain functional skills, and reduces or pre-empts the occurrence of behavior problems. However, the living environment at Pinecrest meets none of these requirements.

The environment at Pinecrest is not fully functional for its residents and may be the cause of some of their problem behaviors. On our tour of Pinecrest, many residents were not interacting with each other, staff, training materials or their environment generally. Skills are taught in isolation, not in a functional context, and the programs are not individualized for each resident. The delivery of services is inconsistent, undermining stability. As discussed earlier, the mere fact that the facility has for years been unable to effectively treat its residents' behavior problems through treatment programs indicates that the State is not providing an acceptable living environment for them. In addition, the environment at Pinecrest is not safe given the number of abuse and neglect investigations undertaken, and given the hundreds of recorded incidents at the facility. In the first ten months of 1994 alone, over eleven thousand pages of incidents were recorded. Not all of these were injuries, but the sheer volume indicates that the environment is not safe.

Moreover, Pinecrest is an isolated, self-contained environment which necessarily separates its residents with disabilities from the rest of society. As a result, the facility fails to provide its residents treatment in an environment that permits contacts with society and its mainstream social institutions, demands independent functioning and permits the exercise of judgment and contact with family members. The State must provide these disabled residents an opportunity to participate in or benefit from aids, benefits and services equal to that afforded to others outside the institution; more specifically, to those provided to other individuals with disabilities in the State's established community-based programs. The residents are entitled to aids, benefits and services that

are as effective in affording them the equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as those served in community-based programs. Pinecrest does not provide the most integrated living environment for its residents and imposes unnatural restrictions. For example, most of the residents have their clothes locked in closets so that they will not be stolen by the staff. Further, most residents are afforded little or no privacy at the facility. In sum, by confining residents with disabilities at Pinecrest, the State is failing to provide such services in the most integrated setting as required by the Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12132 et seq., and Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §§ 794 et seq.

The cases reviewed by our consultant indicate that most if not all of the Pinecrest residents could be successfully placed in the community if provided with adequate supports. In large measure, the State agrees. Deputy Secretary Castille indicated that the State was making a conscious effort to outplace residents. Mr. Wright added that he is a supporter of community placement. In fact, as of November 1994, the facility had already identified about two-thirds of its residents as suitable for community placement. Overall, 630 residents have been identified as "suitable" for community placement, and of those, 189 residents had been referred to and/or are currently on a waiting list for community placement. Most Pinecrest staff admitted that a high percentage of residents (70-100 percent) could be placed out of the facility with the proper supports. Unfortunately, the placement process can take years and staff members have admitted that the individuals stagnate and regress while awaiting placement. Keeping individuals whom professionals have identified as appropriate or suitable for community placement in residential institutions violates the residents' legal rights. 2/

The children and adolescents at Pinecrest are particularly at risk as a result of institutionalization. The clear trend

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2/ See, e.g., Jackson v. Fort Stanton Hosp. & Training Sch., 757 F. Supp. 1243, 1310-13 (D.N.M. 1990), rev'd in part on other grounds, 964 F.2d 980 (10th Cir. 1992); Thomas S. by Brooks v. Flaherty, 699 F. Supp. 1178, 1204 (W.D.N.C. 1988), aff'd, 902 F.2d 250 (4th Cir.), cert. denied, 498 U.S. 951 (1990); Clark v. Cohen, 613 F. Supp. 684, 704 (E.D. Pa. 1985), aff'd, 794 F.2d 79 (3d Cir.), cert. denied, 479 U.S. 962 (1986) (all finding a Fourteenth Amendment right to community services where a professional has determined that an institutionalized mentally retarded client should be served in the community); see also ADA, 42 U.S.C. §§ 12132 et seq. (including implementing regulations, e.g., 28 C.F.R. 35.130(b)(1); and 28 C.F.R. 35.130(d)); Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §§ 794 et seq.

today is to serve and educate children in integrated settings. Seventy-four Pinecrest school-aged residents are served by Special School District 1 ("SSD1"). The school programs our consultant reviewed were generally up-to-date, functional and appropriate for the individual students. Nonetheless, SSD1 is a segregated setting, physically removed from the mainstream, located on the Pinecrest campus. Children with disabilities are legally entitled to an education in the most integrated, least restrictive setting which SSD1 does not provide. For most children this means instruction in a classroom or school with non-disabled children.

D. MEDICAL CARE FAILS TO MEET GENERALLY ACCEPTED STANDARDS

1. General medical care and services are inadequate.

Pinecrest is failing to ensure that its residents receive adequate preventive, chronic, routine, acute, and emergency medical care that comports with accepted standards of care.

The doctors at Pinecrest fail to provide preventive care to the residents, adopting instead a passive attitude towards the care and services they provide to the residents. Most seem to wait until a problem develops before they mobilize to act. Moreover, the medical staff at Pinecrest is failing to provide the residents with adequate medical assessment, diagnosis, treatment and monitoring of their condition in keeping with generally accepted standards of medical care.

The number of deaths at Pinecrest attributable to bowel and intestinal obstruction is excessive and represents a preventable cause of death. Some of the residents have suffered with gangrenous bowel. The doctors do not get involved early enough in the care of the residents with this problem because they mistakenly think of this as more of a "nursing" issue with little or no true medical involvement needed. Providing standing orders for weekly enemas, as is currently mandated, is not generally accepted preventive treatment for this type of condition.

The medical staff members, especially the doctors, are not providing preventive care for those individuals truly at risk of aspirating. The nutritional management team does not screen and provide services to everyone truly at risk of aspirating. This leaves some individuals in need of care without coverage. The team waits until the person suffers an acute, potentially life-threatening event before realizing that he or she has a nutritional, feeding, dysphagia or aspiration problem. At mealtimes, the staff does not always feed the residents in a safe and effective manner.

The facility has placed the residents with tracheostomy tubes at undue risk of death because the replacement tracheostomy

tubes are locked up and located far away from the individual's bedside. If an emergency were to occur, the staff would not be able to replace the individual's trach tube with the replacement tube of correct size and length because it would be locked in a cabinet. This situation is untenable and unduly imperils the residents' health. Further, not all staff members are adequately trained in how to handle a trach emergency.

There are a number of other problems with medical care at Pinecrest that violate generally accepted standards. For example: emergency care at Pinecrest is not adequate with Pinecrest having no capacity to manage a real emergency; the care of insulin dependent diabetic residents deviates from generally accepted practices for those individuals; none of the staff doctors have any familiarity or adequate training with respect to the care and treatment needed for individuals with developmental disabilities; communication between doctors and nurses and staff is problematic at Pinecrest; physician caseloads are too large; the number of medical specialty consult hours are woefully inadequate to meet the residents' needs; Pinecrest fails to maintain adequate, appropriate and unified medical records with proper documentation; the records do not accompany the individual to the in-patient clinic ("IPC"), out-patient clinic ("OPC"), or the hospital leaving the staff there to rely on oral history.

2. Neurological care is inadequate.

Pinecrest is failing to provide adequate routine, chronic, and emergency seizure management to all epileptic residents in accordance with accepted standards of care.

Dr. Diane Africk, the facility's only neurological consultant, provides services to the Pinecrest residents only twice per month for a half-day each visit. The vast majority of residents in need of her services are simply never seen in consult by the neurologist. As a result, the residents do not get the expert care they require. Pinecrest acknowledges that this is unacceptable. Many Pinecrest residents who are treated with multiple anticonvulsant medications (polypharmacy) are never seen by the neurologist. As a result, these residents on anticonvulsant polypharmacy daily face the harm and the risk of harm that result from overmedication and its associated side effects.

Pinecrest has failed to take adequate steps to outline and implement plans, protocols and procedures in the event a resident suffers an emergency episode of prolonged seizures known as "status epilepticus." Pinecrest has issued no protocol nor "inserviced" its staff on how to recognize and react to an episode of status. Pinecrest's standing order for "seizures" mandates the use of soapsuds enemas and intramuscular medication, neither of which are appropriate treatments. In fact, it is

generally accepted that intramuscular therapy has no place in the treatment of status epilepticus. As a result, the facility has failed to provide adequate guidance to staff in how to recognize and treat status.

Pinecrest also deviates from generally accepted practices in the following areas: Pinecrest fails to undertake sufficient testing to determine whether certain events are pseudo-seizures, or are, in fact, seizures; seizure documentation is deficient; some Pinecrest physicians mistakenly label those with epilepsy as also having a carnitine deficiency; Pinecrest residents with neurofibromatosis and tuberous sclerosis are not routinely seen by a neurologist; and Pinecrest generally fails to provide its residents with needed etiologies or documented medical causes of their developmental disorders.

E. NURSING SERVICES FAIL TO MEET GENERALLY ACCEPTED STANDARDS

1. General nursing services and processes are inadequate.

Pinecrest is failing to ensure that its residents receive adequate nursing care, and that Pinecrest nurses perform their responsibilities in keeping with accepted professional standards of care by adequately identifying health care problems, notifying physicians of health care problems, monitoring and intervening to ameliorate such problems, and keeping appropriate records of residents' health care status. Our consultant could clearly see that the existing staff nurses are generally very concerned about the residents and genuinely care for them. However, as she concluded, "caring is not sufficient to keep them from dying or becoming chronically ill."

The nursing assessments at Pinecrest are inadequate and are not in keeping with accepted professional practices. The facility purports to use nursing diagnosis, but what is documented is incomplete, and does not identify potential problems. Pinecrest fails to develop and implement adequate and appropriate comprehensive nursing care plans to address each resident's health care needs. Moreover, the Pinecrest nursing staff fails to routinely perform on-going monitoring of serious medical conditions, and to undertake such basic procedures as taking vital signs and monitoring individual's health status.

Proper monitoring is made especially difficult in the home life areas given that the medical documentation for each resident is so dispersed throughout the facility. The current recordkeeping system makes it extremely difficult and time consuming to try to obtain a comprehensive picture of the status of an individual. The Pinecrest professional staff have even admitted that the recordkeeping is subpar and needs to be improved.

Overall, our consultant concluded and we find that "Pinecrest nurses fail to provide generally accepted, ongoing, accurate assessments, document nursing diagnoses, develop and implement programs of preventive health care, and monitor their effectiveness. Nurses rely too heavily on input from direct care staff which turns a progression of seemingly minor illnesses into chronic health problems requiring repeated hospitalization."

2. Medication error risk is too high.

The daily risk of medication errors and the actual number of medication errors are too high at Pinecrest. Our consultant concluded and we find that "[t]he lack of nursing supervision over direct care staff as they perform nurse related functions, particularly medication administration, clearly puts Pinecrest residents at increased risk of illness, injury, and in a worst case scenario, death." Moreover, Pinecrest does not document or track these errors well. Not all medication errors are written up as incident reports, not all errors are listed in the monthly pharmacy reports, and not all errors were provided to us at our request. Our expert concluded and we find that "it is a fair assumption that the facility really has no idea of the frequency with which medication errors are actually occurring."

3. Nurse staffing and training are inadequate.

The current nurse staffing is inadequate to meet the needs of the Pinecrest residents. The clientele at Pinecrest have very complex medical and nursing needs with many individuals having unique bathing and/or toileting needs. Consequently, a sufficient nursing presence is crucial to their adequate care. However, even the Director of Nursing admitted that nurse staffing was inadequate. Virtually every nurse's caseload is very high. In most of the home life areas, there is no nursing coverage for two thirds of the day, leaving all residents including many non-ambulatory, multi-handicapped individuals who need specialized care, without the services of a nurse. As a result, important nursing duties fall to the direct care staff members who are unable to adequately promote resident health and to prevent and treat illness and long term disabilities.

The Pinecrest nurses need to be inserviced to ensure that they have been provided with the appropriate training to care for the diverse and challenging Pinecrest population. Our nursing consultant concluded and we find that "[t]here is nothing in the pre-service orientation process to prepare nurses either for the management responsibilities of their position. There is nothing in the pre-service that prepares nurses for the ongoing health care needs of individuals with mental retardation/developmental disabilities who are medically complex. Further, there is nothing in the orientation package that deals with the complexities of nutritional management systems, or alternative

positioning in the form of physical management. There is no system in place to train nurses within the facility to perform these functions, let alone monitor the implementation by the direct care staff."

F. NUTRITIONAL MANAGEMENT AND SERVICES FOR THOSE AT RISK OF ASPIRATION DO NOT MEET GENERALLY ACCEPTED STANDARDS

One of the most urgent problems at Pinecrest is the facility's failure to provide each individual with adequate and appropriate nutritional management (specialized services tailored to meet the needs of individuals with eating and/or swallowing difficulties) in accordance with accepted standards of care. This failure has placed many Pinecrest residents at risk of aspirating which is an extremely dangerous, potentially life-threatening situation. Our consultant commented and we find that "[i]t is evident that the individuals residing at Pinecrest with any sort of nutritional management problem are at risk of an early demise." Virtually every resident who died just prior to our visit had some sort of nutritional management problem.

Pinecrest has failed to screen, identify, and assess all residents to find those individuals who have a nutritional management problem, including difficulty swallowing, chewing, or retaining, assimilating or eliminating food and/or liquids, are aspirating, are at risk of aspirating, and/or who have symptoms of gastroesophageal reflux ("GER"). There is no meaningful, ongoing, routine screening system in place at Pinecrest. Because of lack of staff and resources, the nutritional management team is able to provide services only to those "high risk" individuals who have already suffered some sort of acute respiratory event, such as an episode of pneumonia or possible aspiration, and/or have suffered from the most obvious types of feeding difficulties. Thus, the facility is practicing reactive care, not needed preventive care, because the nutritional management team leaves those merely "at risk" without needed services and attention until they become "high risk." By failing to identify residents at early stages, Pinecrest is not intervening when residents' nutritional management problems are most treatable. The facility is also failing to identify all those residents with GER, subjecting them to discomfort and increased risk of aspirating refluxed stomach contents.

For the few persons provided services, Pinecrest is failing to conduct comprehensive, interdisciplinary evaluations and diagnoses for them and is failing to identify their medical, dietary, feeding and positioning needs. The few nutritional management evaluations that are undertaken are not complete, failing to consider, among other things, the effects of poor positioning, current seating devices, adaptive equipment, the appropriateness of the current feeding program, the influence of

other medications, tardive dyskinesia, and behavior management problems, on an individual's risk of aspiration.

There is no skill acquisition training provided to prevent aspiration for those individuals with dysphagia and other eating disorders. Although there are a great many residents with known oral motor problems, no one at the facility has the training to provide oral motor therapy, and they generally fail to provide appropriate oral motor stimulation when necessary. Further, Pinecrest fails to regularly monitor the progress of the Pinecrest residents at risk of aspirating and to take whatever assessment, diagnostic, treatment, or supervision steps are necessary to ameliorate the individual's risk.

Mealtime interventions at Pinecrest are generally not consistent with the needs of the individuals who live there, and as such, do not meet accepted standards. Many Pinecrest residents have behavior problems that cause them to snatch food and overstuff their mouths, drastically increasing their risk of aspiration and sudden death. Nonetheless, the staff typically fails to intervene or redirect the negative feeding behavior.

Pinecrest is failing to ensure that residents are fed using proper techniques and while their bodies are properly positioned. Feeding programs are generally not followed, but when they are attempted, they are implemented poorly and sometimes dangerously. This is related to the professional staff failing to directly supervise the direct care staff during meal times, resulting in improper implementation of the feeding programs. Our consultant concluded and we find that "positioning of residents at meal times is frequently poor with no corrections made by the direct care staff. Individuals who are defined as 'at risk' by the facility, upon observation, are being fed with their necks in hyperextension and in other cases with their necks in such tight flexion that they literally eat with their face in their food." Our consultant provided a number of examples of such dangerous and improper feeding techniques which caused many individuals to cough and gag. One such example is particularly poignant:

> On observation, [T.G.'s] neck was in hyper-extension, her hips were flexed out away from the back of the wheelchair, she was sitting in urine, and the caregiver was feeding her at a rate so fast that she could never finish one mouthful before the next was presented. As a result of this combination of factors, Ms. G. was coughing and gagging so badly that I felt that I had to intervene. By correcting her position, counselling the staff about the rate of feeding, and requesting that her wet clothing be changed, a potentially life-threatening situation was averted. I do not believe that this is an overly dramatic statement, given that Ms. G. has already had two episodes of suspected aspiration which required transportation to the local hospital.

Our consultant concluded and we find that "the facility has failed to provide a safe, structured, mealtime program for its residents. The systems in place do not contain integral components of generally accepted nutritional management. Any attempt at providing such services are seriously flawed and generally not implemented."

G. OCCUPATIONAL AND PHYSICAL THERAPY SERVICES DO NOT MEET THE NEEDS OF THE RESIDENTS

1. Occupational therapy services are inadequate.

Pinecrest fails to provide its residents with sufficient occupational therapy ("OT") services. In fact, in response to our request for information, Pinecrest replied: "There are currently no clients who are picked up in actual Occupational Therapy." Of the many resident records our consultant reviewed, most individuals had never been provided with an OT evaluation or even a routine screening, nor had they been assessed for risk of choking. Of the individuals reviewed, all needed specialized OT services because all had feeding problems, had been hospitalized repeatedly or even died. The head of Pinecrest OT services admitted that she does not have sufficient OT staff to provide the residents with the OT they need. As a result, the residents receive reactive OT, not the preventive OT they require. Residents only receive OT when it is too late, and they are already seriously in need of intervention.

Our consultant concluded and we find "[t]here is no consistently implemented plan of care, for which OT assumes responsibility for either implementing or monitoring. There is no system in place to prevent deterioration. There is insufficient OT staff, education, and resources to meet the needs of the individuals at Pinecrest."

2. Physical therapy services are inadequate.

Pinecrest fails to provide adequate physical therapy ("PT") services to the residents. PT staffing and consult hours are insufficient. Few of the individuals our consultant reviewed had been provided with a PT evaluation. In fact, most of those evaluations were over ten years old. Our consultant concluded and we find "[i]t is obvious that there is no physical therapy system in place at Pinecrest to evaluate the needs of individuals until they reach a point where the deformity has deteriorated and it catches the attention of the RTSs ... PT is trying to provide nothing more than acute care services. Unfortunately for the residents, Pinecrest serves a population with chronic care needs ... discussion of physical management as an ongoing system of integrated services aimed at both correcting and preventing deformities is a moot point. It does not exist at Pinecrest."

H. FEDERAL STATUTORY VIOLATIONS

In addition to the above constitutional, statutory and regulatory violations, we note the many outstanding historical violations, cited by the Health Care Financing Administration, of the Medical Assistance Program (Medicaid), established under Title XIX of the Social Security Act, 42 U.S.C. §§ 1396r et seq., and the regulations promulgated pursuant thereto.

I. MINIMAL REMEDIAL MEASURES

In order to remedy these deficiencies and to protect the rights of the Pinecrest residents, the following measures, at a minimum, need to be implemented promptly.

1. Most Integrated Setting

The State must provide services to individuals with developmental disabilities in the most integrated and normalized setting appropriate to their needs. To this end, the State must:

a. Conduct an adequate assessment by appropriate professionals of each Pinecrest resident who has not yet been determined to be "suitable" for community placement to determine whether each resident is in the most integrated setting appropriate to the resident's needs;

b. For those already identified by the facility, and identified through the assessment process in "a." above as "suitable" for community placement, identify the required residences, day programs, including vocational opportunities, specialized services, including medical care and related services, and other supports needed to serve these individuals in the community;

c. Develop a comprehensive community placement plan to expand and establish community residences and services to meet the individual needs of the residents identified as "suitable" for community placement; establish a schedule to place such individuals in community-based programs with priority placed on children at Pinecrest;

d. Place such individuals into community-based programs that meet their individual needs; conduct monitoring of community-based programs to ensure program adequacy and the full implementation of each individual's habilitation plan.

2. Psychological Services and Training Programs

Pinecrest must provide an adequate array of comprehensive individualized training programs for the residents developed by qualified professionals consistent with accepted professional

standards to reduce or eliminate risks to personal safety, unreasonable use of bodily restraints, prevent regression, and facilitate the growth, development, and independence of every Pinecrest resident. To this end, Pinecrest must:

a. Conduct a comprehensive interdisciplinary evaluation of each Pinecrest resident to determine the individual's need for training;

b. Develop and implement a professionally based, individually appropriate data collection system to measure relevant information about maladaptive behaviors and the conditions under which they occur, including, where appropriate, the frequency, intensity, and duration of the behaviors;

c. Have a qualified professional develop and implement and monitor a professionally based, individualized training program for each resident and provide each individual with an adequate number of hours of training.

Pinecrest must ensure that bodily restraints, including time out, are used only pursuant to accepted professional standards and that they are never used as punishment, in lieu of training programs, or for the convenience of staff. Pinecrest must implement a protocol that has as its goal the elimination of routine use of emergency chemical and unplanned physical or mechanical restraints.

3. Psychiatric Care

Pinecrest must provide adequate and appropriate routine and emergency psychiatric and mental health services in accordance with accepted professional standards to residents who need such services. Pinecrest must procure adequate psychiatry consult hours to meet the needs of the residents. Psychotropic medication must only be used in accordance with accepted professional standards and must not be used as punishment, in lieu of a training program, for behavior control, in lieu of a psychiatric or neuropsychiatric diagnosis, or for the convenience of staff. Pinecrest must:

a. Conduct a comprehensive assessment of each Pinecrest resident receiving psychotropic medication;

b. Develop an overall treatment plan for each resident with a diagnosis of mental illness with a description of clear, objective and measurable short-term, intermediate and long range goals and objectives for each resident including time frames for the achievement of each, and provide on-going monitoring of the treatment;

c. Document that, prior to using the psychotropic medication for behavior modification, other, less restrictive techniques have been systematically tried as part of a training program and have been demonstrated to be ineffective;

d. Develop and implement an adequate system for detecting, reporting, and responding to any drug-induced side effects of psychotropic medication.

4. Medical Care

Pinecrest must ensure that its residents receive adequate preventive, chronic, routine, acute, and emergency medical care in accordance with generally accepted standards of care. To this end, Pinecrest primary care physicians must:

a. Conduct comprehensive evaluations of all residents for whom they are responsible;

b. Determine what specialized medical services are required for the residents for whom they are responsible and ensure that such services are timely obtained whenever necessary to evaluate or treat the individual's medical problems;

c. Ensure that each individual has an integrated medical plan of care to address any chronic medical problem;

d. Ensure that each individual's medical status and progress in response to the individual's medical plan of care is regularly and adequately reviewed.

In concert with the steps above, Pinecrest must provide adequate and appropriate routine, chronic, and emergency seizure management to all individuals with epilepsy at Pinecrest in accordance with accepted professional standards of care. Specifically, the State must procure a sufficient number of neurology consult hours to meet the needs of the residents, bolster seizure documentation and recordkeeping, and improve diagnostic techniques. Pinecrest must put in place an emergency protocol for the treatment of status epilepticus and "inservice" staff on how to implement it. Pinecrest must immediately stop use of intramuscular medication to treat status.

5. Nursing Care

Pinecrest must ensure that its residents receive adequate nursing care, and that nurses perform their responsibilities in keeping with accepted professional standards of care by adequately identifying health care problems, notifying physicians of health care problems, monitoring and intervening to ameliorate

such problems, and keeping appropriate records of residents' health care status. To this end, Pinecrest nurses must:

a. Conduct adequate, comprehensive assessments;

b. Develop nursing diagnoses and develop and implement adequate and appropriate comprehensive nursing care plans to address each resident's health care needs;

c. Routinely perform on-going monitoring of serious medical conditions, including such basic procedures as taking vital signs and measuring weights;

d. Develop and implement a system for recording important information about a resident's status to monitor changes.

6. Nutritional and Physical Management

Pinecrest must provide adequate care for those individuals at risk of aspirating. To this end, Pinecrest must:

a. Identify all individuals who are at risk of aspirating;

b. Take any appropriate steps to ameliorate the individual's aspiration risk and develop and implement an individualized feeding and positioning plan for each individual identified as at risk of aspirating;

c. Develop and implement a system to regularly monitor the progress of the Pinecrest residents who are at risk of aspirating to ensure that the staff is continually taking whatever assessment, diagnostic, supervision and treatment steps are necessary to ameliorate the individual's risk.

Pinecrest must provide each resident with adequate and appropriate nutritional management in accordance with accepted standards of care. To this end, Pinecrest must:

a. Identify each individual who has a nutritional management problem, including dysphagia, difficulty swallowing, chewing, or retaining, food and/or liquids;

b. Have an interdisciplinary team of oral motor specialists comprehensively assess each such individual to identify the causes for the nutritional management problems;

c. Take necessary steps to ameliorate the problem;

d. Develop adequate feeding plans for residents who cannot feed themselves, including feeding techniques and positioning of the resident during feeding; train staff in how to implement the plans; and monitor the implementation

to ensure that the staff safely and appropriately feed the residents;

e. Develop and implement a system to regularly monitor the progress of the Pinecrest residents with nutritional management difficulties to ensure that staff members are continually taking whatever assessment, diagnostic, supervision and treatment steps are necessary to ameliorate the individual's difficulties.

Pinecrest must provide each resident with adequate and appropriate physical therapy and occupational therapy services in accordance with accepted standards of care.

7. Recordkeeping and Staffing

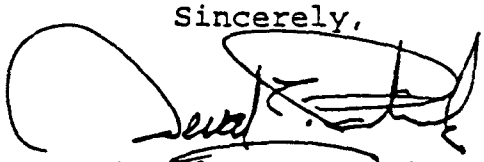
Pinecrest must establish and maintain an adequate, unified record for each individual that comports with accepted professional standards that must include current information with respect to his/her care, medical treatment, and training, and must require staff to utilize such records in making care, medical treatment and training decisions.

The State must ensure that a sufficient number of professional and non-professional staff, including outside consultants, are employed to fully meet the needs of the Pinecrest residents. In particular, Pinecrest must increase the number of psychologists, nurses, physical therapists, occupational therapists, and hours of neurology and psychiatric consultation. The State must ensure that the staff is adequately trained to perform its duties.

Given our positive experience with the State thus far, we fully expect to be able to resolve this matter amicably and cooperatively. Nonetheless, we must inform you pursuant to CRIPA, the Attorney General may initiate a lawsuit to correct deficiencies at an institution or otherwise to protect the rights of its residents 49 days after appropriate officials have been advised of the relevant violations of law. 42 U.S.C. § 1997b(a)(1). Therefore, we anticipate hearing from you as soon as possible but no later than 49 days after the date of this letter with any response you may have taken or intend to take to implement each of the remedies described above. If you do not respond within the stated time period, we will have to consider initiating an action to remedy the unconstitutional and unlawful conditions we have identified. In your response, please address your willingness to enter into a judicially enforceable agreement to memorialize any agreement we may subsequently reach.

We look forward to working with you to resolve this matter in a reasonable and practical manner. If you or your staff has any questions, please contact Richard Farano at 202-307-3116.

Sincerely,



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