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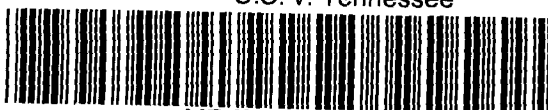



Honorable Ned McWherter
Governor of Tennessee
Governor's Office
State Capitol
Nashville, Tennessee 37219

Re: Findings of Investigation, Arlington Developmental Center

Dear Governor McWherter:

By letter dated July 11, 1990, we notified you that, pursuant to the Civil Rights of Institutionalized Persons Act, 42 U.S.C. §1997 et seq., the Civil Rights Division of the United States Department of Justice was commencing an investigation into conditions at Arlington Developmental Center (Arlington), a facility for mentally retarded persons located in Arlington, Tennessee. As specified by the statute, we are now writing to inform you of the conditions at Arlington that we have found are depriving residents there of their constitutional and Federal statutory rights, the facts supporting our conclusions, and the minimum measures we believe may remedy those conditions.

Our investigation consisted, first, of several comprehensive tours of Arlington with independent experts, most recently on December 14 and 15, 1990. We observed conditions in all the residential units of Arlington at various times of the day, interviewed administrators, staff and residents, and examined a variety of records. Further, we gathered and analyzed documentation relating to the operation of Arlington, including, but not limited to: a variety of policies and procedures; information relating to staffing; minutes from various committees; incident and injury reports; mortality reviews; abuse investigations; list of residents on medications; and residents' records. Throughout the investigation, we received complete cooperation from the administrators and staff at Arlington. We look forward to continued cooperation.

Based upon our extensive investigation, we have concluded that conditions at Arlington deprive its mentally retarded residents of their constitutional rights to adequate medical care, reasonable safety, and such training as an appropriate professional would consider reasonable to ensure their safety and freedom from undue bodily restraints, Youngberg v. Romeo, 457 U.S. 307, 324 (1982). These conditions, which seriously threaten residents' health and safety, include:

1. Neglect and abuse of residents.

2. Failure to provide adequate medical care, specifically:

   (a) Failure to adequately diagnose and treat residents.

   (b) Failure to provide essential physical therapy services.

   (c) Failure to provide sufficient numbers of appropriately trained staff to render and implement professional judgments regarding necessary medical treatment.

3. Failure to provide required training to residents, specifically:

   (a) Failure to provide professionally designed individualized training and behavioral programs.

   (b) Failure to provide sufficient numbers of appropriately trained staff to implement professional judgments regarding training of residents.

4. Failure to provide a free appropriate public education for school-age residents as required by the Education of the Handicapped Act.

5. Failure to provide a safe environment.

Set forth below are our findings and recommendations.

1. Arlington Residents Are Subjected to Neglect and Abuse.

The failure to provide care or training that a qualified professional would consider appropriate can be deemed "neglect." At Arlington, however, lack of care sometimes rises to active neglect, neglect that harms residents, many of whom spend their

lives at the facility. One consultant who recently toured the facility voiced the concern that:

> Arlington has failed to implement even the most basic changes of the twentieth century. They are providing only the proverbial three hots and a cot. In doing so, they are creating a new generation of multihandicapped individuals, when in some cases, there is no need for these handicaps to exist, other than neglect.

During the investigation, we observed young children, some as young as two, whose limbs were severely contracted. Our experts believed that these contractures were avoidable. Many residents were left unattended in cribs, with no efforts being made to move their limbs, position them, or to provide any real physical therapy services. The failure to actively move, reposition, and exercise such residents results in potentially crippling and irreversible physical deterioration. We observed one five year old boy, unattended in his crib, hitting the side of his head with his fist due to a lack of stimulation. No one was paying attention to the boy other than an overworked direct care worker holding his arm when and <u>if</u> she observed the behavior. The penis of another resident, a paraplegic with an in-dwelling Foley catheter, was eroded throughout its entire length due to inadequate care and monitoring. In many units, there was a pervasive smell of urine. Residents in diapers were wet; often their clothes were soaked through with urine. Besides the direct care staff shortages that permitted these conditions, there was an apparent tolerance of such conditions as well. Our experts concluded that this lack of care constitutes active neglect.

In three abuse investigations that we reviewed, outside physicians who were consulted by residents' families concluded that the residents had been abused. These were the <u>only</u> abuse investigations in which outside physicians had examined the injured Arlington residents. In these three cases, Arlington discounted the outside physicians' findings. As such, the investigations undertaken by Arlington and/or the Department of Human Services (DHS) reveal a lack of commitment to uncovering such abuse or neglect, and, therefore, imply tolerance for such actions. A number of staff reported that it would serve no purpose to report abuse to the administration of Arlington; nothing would be done. This belief is confirmed by one case that we reviewed. In that case, direct care staff who belatedly reported that another direct care worker had abused a resident were disciplined more harshly for the late reports than was the staff member who abused the resident and her supervisor who witnessed and had not reported the incident. Certainly, the message sent to those staff members was not to report such incidents. The obvious result of this apparent tolerance of abuse and lack of vigor when investigating such cases is harm to

Arlington residents. Because reporting of abuse is discounted by Arlington, staff are not trained in detection of abuse and independent opinions are not sought to ascertain whether suspicious injuries are the result of abuse.

We have concluded that abuse is occurring at Arlington. Our conclusion that Arlington residents are being abused is not limited to physical abuse. Our investigation revealed that staff at Arlington have verbally abused residents. These actions have apparently also been tolerated or discounted by the administration.

2. Arlington Residents Do Not Receive Adequate Medical Care

a. Failure to adequately diagnose and treat residents.

Our consultant found that Arlington lacks long range planning for managing residents with chronic medical conditions. Routine procedures for testing residents' blood levels and monitoring the course of chronic diseases were not implemented. For example, routine testing of vomitus for blood was not accomplished for a resident who, on numerous occasions, had symptoms of gastric bleeding. Our consultant found that the failure to order such tests substantially departed from accepted medical practice. There were inadequate efforts to diagnose residents' problems, a process essential to appropriate treatment and evaluation of the efficacy of treatment. As a result, residents' physical conditions have deteriorated. In fact, five Arlington residents have died since October 10, 1990. The medical care provided to these residents, three of whom were less than 23 years old, was inadequate. Additionally, Arlington does not have a system to detect the onset of insidious illnesses. Because changes in residents' physical conditions are not routinely identified or monitored, their conditions may deteriorate and become quite serious before medical treatment is initiated. We have concluded that the care and treatment of residents with chronic conditions substantially departs from accepted medical practice.

Our consultants found that Arlington has no procedure for monitoring the effectiveness of medications prescribed. As a result, residents are not treated for side effects or may continue to receive medications that are not effective and do not resolve their medical conditions. Generally, our consultants found that documentation of medical evaluations and treatment is inadequate, especially for residents with more serious and chronic diseases. Due to a failure to document ongoing health care problems, Arlington does not provide adequate preventative health care. There are also unacceptable delays in placing hospital communications, i.e., discharge summaries and emergency room reports, in residents' charts. Because current and complete medical information is not maintained in the chart, professional

and direct care staff lack important information on which to base their judgments and services. This deficiency subjects residents of Arlington to unnecessary risk of harm from inappropriate treatment decisions.

Our consultants found that Arlington does not attempt to diagnose residents' underlying psychiatric disorders and fails to monitor positive and negative effects when psychotropic medications are prescribed. Some residents receiving psychotropics do not benefit from them, while others who might benefit do not receive them. Our consultants also found that Arlington automatically reduced or eliminated such medications with inadequate justification. In light of the above, our consultants concluded that psychotropic medications are not being prescribed or monitored consistent with professional standards. Because such medications can have serious deleterious side effects, prescription of the wrong medication and failure to properly monitor them subjects residents to undue risk of harm. Additionally, there is a significant danger that psychotropic medications may be used as chemical restraints.

Our consultants found that residents are not referred to or seen by consulting physicians as frequently as their conditions require. Specifically, residents with neurological and orthopedic problems and conditions are not identified, managed, evaluated, or treated consistent with the judgment of qualified professionals. Our consultants observed residents having seizures whose seizure activity was not noticed by Arlington's direct care and nursing staff. Such failure to identify and record seizure activity clearly results in harm to these residents. Dramatic evidence of the failure to manage such conditions was the death in December of a resident who had been having numerous seizures and is believed to have died as a result of a seizure. Our expert concluded that the medical care provided this resident was clearly inadequate. The predictable result of these deficiencies in medical care is unnecessary risk of harm to Arlington residents.

b. Failure to provide essential physical therapy services.

After an exhaustive review of the physical therapy services offered at Arlington, our consultant concluded that Arlington is failing to adequately provide such services and that such failure constituted a serious deficiency in residents' medical care. In a population of approximately 250 physically handicapped residents, none receive hands on therapy from a physical therapist. Moreover, our expert found that residents' physical therapy programs are not individualized and do not address their specific needs. The failure to provide necessary physical therapy services results in contractures, physical degeneration, inappropriate body growth, and deformity that, in turn, subjects residents to eating, digestion, and general medical problems

(e.g., respiratory difficulties due to scoliosis). The failure to provide appropriate evaluations, goals, and services often results in physical deterioration. Our consultant found that Arlington's improper positioning of residents has actually increased their deformities. She found that such harm was attributable to both inadequate and inappropriate physical therapy programs and inadequate numbers of adequately trained staff.

Our consultant physical therapist concluded that the use of adaptive equipment at Arlington often does not reflect the exercise of judgment by a qualified professional. Inappropriate use of such equipment jeopardizes the health and safety of residents. Ill-fitting adaptive equipment, including wheelchairs, does not provide adequate support, thereby increasing the risk of accidental injury and physical deterioration. Numerous residents who once sat in wheelchairs are now confined to carts. This is dramatic evidence of such physical deterioration. Our consultant found that the deformities of these cart-bound residents were a result of improper positioning and inadequate physical therapy services. Additionally, the carts themselves are dangerous. Incident reports reviewed during the investigation reflect that a number of residents have been injured when they fell out of unstable carts. Moreover, our nurse consultant observed that Arlington is not providing adequate assistive devices to enable residents to walk and move. The natural result of the failure to provide such devices is resident injury and physical deterioration.

Arlington is failing to provide physical therapy services and staff to render appropriate and necessary care to address the physical therapy needs of the residents of Arlington and to implement physical therapy services programs consistent with qualified professional judgment. See Youngberg v. Romeo, supra, at 324.

(c) Failure to provide sufficient numbers of appropriately trained staff to render and implement professional judgments regarding necessary medical treatment.

Our investigation revealed that the nursing department is critically short staffed. There are not enough adequately trained nurses at Arlington, a deficiency that places residents at an unreasonable risk of harm. For example, our consultant observed nurses inappropriately dispensing medications to physically handicapped residents, e.g., by means of a tongue blade placed down residents' throats. Our consultant found that this method of medicating physically involved residents may result in harm. Nurses are not promptly hired to replace those that leave. Because of these shortages, nurses often "float" to areas to which they are not typically assigned and where they are

responsible for caring for residents with whom they are not familiar. It is not unusual for one nurse, assigned to a unit as a floater, to administer medications to 128 residents twice in one 8 hour shift. The potential for medication errors in such circumstances is obvious. While Arlington officially reported only two medication errors over a time frame, our consultants' review of residents' records as well as information obtained from other sources suggests that these figures seriously underrepresent the breadth of that problem at Arlington.

At the time of our latest tour, December 1990, there were only three physicians, including the Medical Director, to provide medical care to almost 500 developmentally disabled Arlington residents. Many of these residents have serious physical disabilities and complex medical needs. In our expert's view, three primary care physicians are not sufficient to examine 500 residents, review their charts, adjust their medications, and keep abreast of their medical condition, i.e., to render decisions with respect to care that are consistent with professional judgments. The shortage results in a failure to adequately manage, evaluate, and treat chronic medical conditions.

While Arlington has contracted with a number of specialists to examine and treat its residents, our experts consider that the hours contracted for are not sufficient to provide a level of care consistent with professional standards. For example, Arlington has a contract providing for neurology consultation three times per year. This is not adequate to properly evaluate, treat, and follow the more than 260 residents with seizure disorders. Similarly, of those residents' records that we reviewed, a majority of residents with physical disabilities had not received an orthopedic consultation within the past two years. Our investigation also revealed that necessary orthopedic surgery is not recommended or undertaken because appropriate therapy and follow-up is not available. In our consultants' opinion, given the serious physical impairments of many of Arlington's residents, this level of consultation and care is seriously inadequate.

As discussed above, there is a critical shortage of physical therapists. There are approximately 250 residents in need of physical therapy services; Arlington contracts with two part-time physical therapists who work a combined total of 28-30 hours per week. Our consultants concluded that 30 hours per week is totally inadequate to provide necessary physical therapy services to all Arlington residents who need them. Additionally, the direct care staff receives no training in physical management and positioning of these physically handicapped residents. Our consultants found that the failure to move, reposition, exercise, and provide hands on physical therapy to such residents leads to physical deterioration and other harm.

Staff at Arlington does not adequately identify or care for residents with impaired eating ability. Staff fail to properly position residents during meals, utilize appropriate feeding techniques, and effectively monitor residents. Because of this, Arlington residents face serious risks of aspiration, a leading cause of death among institutionalized developmentally disabled populations. Our experts personally observed residents coughing and choking on food and mucus during meals. Aspiration pneumonia accounted for at least three of the seven pneumonia-related hospital admissions of Arlington residents in the period from July 1, 1990, to December 15, 1990. One of the five recent deaths of Arlington residents was caused by aspiration pneumonia.

After two of our tours, our consultants requested that we immediately convey to Arlington staff their concern that these conditions were life-threatening to residents. We did so. However, despite the serious risks of aspiration, Arlington fails to ensure that residents are fed safely.

3. Arlington Residents Do Not Receive Adequate Training.

a. Failure to Provide Training Required by Youngberg.

Following a careful review, our consultant psychologist concluded that the lack of training programs for Arlington residents results in injury and the unreasonable risk of injury (to self and others). Instances of self-abuse were not uncommon; observed attempts to intervene appropriately were rare. Many residents were observed to have unexplained cuts, bruises and scrapes. Our expert concluded that the current practice of behavior modification at Arlington fails to reduce aggressive and other maladaptive and inappropriate behaviors. Moreover, Arlington does not provide adequate psychological services to children to prevent them from developing self-abusive behaviors. Clearly, many of the injuries we observed may have been preventable had programs been implemented and if more trained staff were available.

As a result of Arlington's continuing failure to design and implement adequate training programs, residents suffer otherwise preventable physical injuries, either self-inflicted or from other residents. Approximately 40% of the injuries in a representative sampling of Arlington residents were reported as either self-inflicted or caused by other residents. Reducing aggressive and other maladaptive and inappropriate behaviors through appropriate behavior modification and training would significantly reduce such injuries.

Our consultants found that, although the great majority of Arlington's residents are diagnosed as severely or profoundly mentally retarded, many are misdiagnosed. Arlington does not have adequate diagnostic criteria to determine degrees of

ability. As a result of inaccurate diagnoses, the meager training provided these residents is inappropriate.

Our investigation also revealed that there are many severely physically handicapped residents who are misdiagnosed as severely or profoundly mentally handicapped because of their physical limitations. As a result of such misdiagnoses, residents do not receive programming that qualified professionals would consider necessary. For example, many such residents are not provided the means to communicate through communication boards or other assistive communication devices even though they are capable of learning such skills that would enable them to communicate their needs, including their needs for specific care or treatment. The failure to provide residents with means to express their needs results in harm and possible injury.

Our experts found that most of the training plans and behavioral programs do not address the individual needs of the residents and often contained inappropriate or incompatible goals. Our expert found identical plans and programs for residents who appeared to be functioning at different levels; additionally, the programs were unchanged from one year to the next. The lack of individualized programs and the failure to revise and update such programs represent a substantial departure from accepted professional practice.

Arlington residents do not have access to adequate and necessary programs, i.e., work-related, age appropriate fine and gross motor activities, to maintain their current level of functioning. Our consultant found that the dearth of such programs harms residents in two ways. First, because they are not provided with appropriate stimulation, residents may resort to self-abusive or other maladaptive behaviors. Second, in the absence of such programs, deterioration of physical and mental functioning is likely. As a result of this deficiency, residents of Arlington are at a substantial risk of harm.

We additionally found that behavioral records are not maintained and progress data is not collected in a consistent fashion and is not reliable. Inaccurate or incomplete behavioral data collection and recordkeeping present an active danger to residents by depriving professional and other staff of information necessary to make professional, appropriate, and safe decisions regarding training.

b. Inadequate numbers of and insufficiently trained staff to permit the training required by Youngberg.

Our experts concluded that the three full time and two part time (3.5 FTE) psychologists at Arlington -- the persons who are responsible for the design, implementation, supervision, and evaluation of training programs to ensure resident safety and

freedom from undue restraint -- are clearly inadequate to render professional judgments with respect to the care and training of Arlington residents. Each of these psychologists has a caseload of approximately 140 residents. Our consultant found that a caseload of this size is clearly too large to provide adequate treatment for Arlington residents who require psychological services. Moreover, there are no doctoral level psychologists on staff to supervise other staff functioning as psychologists. An inadequate number of trained psychologists has resulted in a failure to develop consistent and necessary treatment and training programs, to implement and monitor them, and to collect and record accurate and pertinent progress data. As a result, residents are at substantial risk of harm.

The safety of Arlington's residents is endangered by inadequate numbers of insufficiently trained direct care staff. Our investigation found that a majority of day and evening shifts, shifts that are scheduled to have a 1:4 staff to resident ratio, in reality function with a ratio of 8 or more residents for each direct care staff. As a consequence of direct care staff shortages, we observed a widespread failure to appropriately manage maladaptive behavior. In one unit, our consultant observed four residents engaging in self-injurious behavior. No staff members intervened. In another unit, a woman repeatedly banged her face against her arm brace. Once again, no staff intervened.

The direct care staff does not possess the technical competence to adequately supervise and train residents of Arlington. In addition, they were generally unfamiliar with residents' behavior programs. Training given to the staff is insufficient in depth and scope to enable them to adequately and effectively provide essential care to residents. As a result of inadequate numbers of inadequately trained direct care staff, residents fail to receive adequate daily supervision and training. This failure contributes to an alarmingly high frequency of injuries, 20% of which are of unknown cause. As a consequence of the foregoing, residents of Arlington are exposed to serious risks to their health and safety.

4. Arlington School-Aged Residents Are Not Provided A Free Appropriate Public Education As Required By The Education Of The Handicapped Act.

One hundred and sixteen school-aged children reside at Arlington. We have concluded that they are not being provided a free appropriate public education required under the Education of the Handicapped Act, 20 U.S.C. §1400 *et seq*. (EHA). Specifically, none of these children attend school off the grounds, although a public elementary school is located a very short distance from the facility. Arlington has two educational programs for the children who live at the facility. One group is

sent to a building on the grounds where they attend classes; the other, consisting of more medically fragile children, attends classes in the residences. The classroom building has been closed for asbestos removal since August 1990 and had not reopened at the time of our latest tour in December 1990. Therefore, all children have attended classes in their residences thus far in this school year. Under the EHA, handicapped children are required to be provided a free appropriate public education with non-handicapped children whenever possible. This requirement is clearly being violated. Moreover, our review of residents' Individual Education Programs confirms that the number of hours residents attend classes as well as the length of the school year does not meet the EHA's standards.

5. Arlington Residents Are Not Provided A Safe Environment.

Our consultant found a number of serious fire safety hazards at Arlington. He identified a major fire safety hazard in the Baker Building, the building that houses both the Infirmary and Arlington's most physically involved residents. All fire exits lead to a confined passageway that does not have appropriate protections to permit the residents, many of whom are confined to wheelchairs or carts, the time to exit safely in case of a fire. Our investigation revealed that the majority of Arlington's residential units do not meet the level of safety required by professional standards due to structural deficiencies (for example, inadequate partitions), doors that are not fire resistent, failure to provide necessary smoke detectors or sprinklers, or inappropriate storage of combustible materials. As a consequence, residents of Arlington are exposed to serious risks to their health and safety.

Minimally Necessary Remedies

Based upon the circumstances discussed above, we have concluded that Arlington residents are being subjected to egregious or flagrant conditions that deprive them of their constitutional rights pursuant to a pattern and practice of resistance to the full enjoyment of those rights. In order to eliminate the conditions that cause these deprivations, at a minimum, Arlington must implement the following remedies:

1) The State must not abuse or neglect Arlington residents and must establish a system to assure that allegations of abuse and neglect are investigated thoroughly and that appropriate action, commensurate with the nature of the offense, is taken against anyone who inflicts, condones, or fails to report abuse or neglect.

2) The State must provide adequate medical care to Arlington residents, including identification, treatment, and management of their acute and chronic medical conditions.

3) The State must provide professionally designed feeding programs for the residents at Arlington who need them, and assure that such programs are appropriately implemented by trained staff in order to protect residents from risks of harm, particularly from aspiration pneumonia.

4) The State must identify all residents who need physical therapy and must provide professionally designed physical therapy programs appropriately implemented by trained staff. The State must ensure that adaptive equipment provided to physically handicapped residents is individualized and appropriate and that a qualified professional oversees its design, use, and repair.

5) The State must provide professionally designed training programs to the residents at Arlington who need them and for whom training will reduce or eliminate unreasonable risks to their personal safety and/or the need to use undue bodily and chemical restraints, and must ensure that such programs are implemented by trained staff. Immediate attention must be given to residents with self-injurious, physically abusive and other destructive behaviors by identifying them and providing necessary training on a priority basis.

6) The State must hire, deploy, and provide ongoing training to a sufficient number of competent and qualified direct care and professional staff to provide residents at Arlington with adequate medical treatment, physical therapy, physical management and positioning, and training programs. Particular attention should be given to ensuring that professional staff receive continuing medical education so that they are equipped to provide adequate long-term care for medical problems commonly found in residents living in facilities for the mentally retarded.

7) The State must hire or contract for the services of sufficient physicians to provide residents with adequate medical and psychiatric services.

8) The State must assure that school-aged children receive a free appropriate public education, including mainstreaming for those children who are capable of attending school off grounds. Children who attend

school at Arlington must be provided a professionally designed individualized education program suited to their needs, and one that provides each student with an appropriate length of school day and school year.

9) The State must remove fire hazards and make appropriate renovations to protect the safety of Arlington residents.

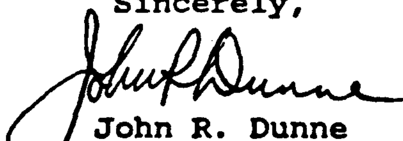
10) The State must assure that Arlington develops and implements recordkeeping systems to monitor the use and effectiveness of behavior and other programs and training, and the use of medications, and ensure periodic re-evaluations of such use.

To rectify the deficiencies at Arlington and to ensure that constitutionally adequate conditions are maintained thereafter, we propose to negotiate an agreement with the State of Tennessee, to be entered as an order of a federal court, which shall provide, at a minimum, that the above referenced remedies will be implemented at Arlington.

Information about Federal financial assistance which may be available to assist with the remedial process can be obtained through the United States Department of Health and Human Services' Regional Office (Director, Intergovernmental and Congressional Affairs), and through appropriate officials of the United States Department of Education.

Our attorneys will be contacting legal counsel for the Tennessee Department of Mental Health and Mental Retardation 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) 514-6255. 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 toward an amicable resolution of this matter.

Sincerely,



John R. Dunne
Assistant Attorney General
Civil Rights Division

cc: Honorable Charles Burson
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State of Tennessee

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