

U.S. Department (ustice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

January 10, 1995

The Honorable Ned McWherter Governor State of Tennessee State Capitol Nashville, Tennessee 37219



Re: Greene Valley Developmental Center

Dear Governor McWherter:

On June 23, 1994, We advised you of this Department's intent to investigate conditions at the Greene Valley Developmental Center ("GVDC") in Greeneville, Tennessee, pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997, et seq. During the week of September 19, 1994, we toured the facility accompanied by consultants in the fields of medicine, psychology, nursing and physical therapy. We wish to express our appreciation for the cooperation shown by the GVDC staff and the representatives from the Department of Mental Health and Mental Retardation and the Attorney General's office during this investigation. On September 24, 1994, we conveyed to the facility superintendent and other state officials an initial assessment of deficiencies at the facility. Our full assessment of conditions at GVDC has now been completed.

We regret to advise you that we found numerous conditions at GVDC that violate the constitutional and federal statutory rights of the residents there. Under the Fourteenth Amendment and relevant federal statutes, residents of state-operated facilities for the developmentally disabled and mentally retarded have a right to, inter alia, adequate medical care, reasonably safe conditions, and training sufficient to protect each resident's liberty interests, including training to permit each resident an opportunity to function as independently as possible. Programs must be provided to teach adaptive skills, including self-help, communication, and social skills. In addition, individuals with developmental disabilities must be provided services in community-based programs where appropriate. 1/

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In addition, GVDC is not in compliance with the Americans with Disabilities Act of 1990, 42 U.S.C. § 12101, et sec., Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, et sec., the substantive provisions of Title XIX of the Social Security Act, 42 U.S.C. § 1396, et sec., and the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §§ 1400 - 1485.

The facts disclosed during the course of our investigation that support our findings of unconstitutional conditions and violations of federal statutory rights at GVDC are set forth below.

I. Medical Care is Dangerously Deficient.

A. General Medical Care

Due to an inadequate medical care delivery system, especially the failure to provide adequate preventive and chronic care, GVDC residents are subjected to needless fractures, recurrent aspiration, preventable weight loss, recurring seizures, avoidable injuries, and other direct threats to their health. Records of residents reviewed by our medical consultant indicate, for example, repeated fractures over many years absent preventive measures; recurrent aspirations, dysphagia and pneumonias without a coherent management plan to treat and otherwise address these life-threatening ailments; significant, rapid weight loss representing a direct threat to health which was often not acknowledged or acted upon by professional staff; multiple drug use absent adequate justification; and other misdiagnosed or untreated injuries. Significantly, the lack of individual or facility-wide data with respect to these urgent medical needs of residents not only compromises the care of individual residents, but limits the ability of the medical staff and administration to properly allocate resources, develop plans,

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Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794,
et seg.; Title XIX of the Social Security Act, 42 U.S.C. § 1396,
et seg. (and implementing regulations, 42 C.F.R. § 483.420 480); Youngberg v. Romeo, 457 U.S. 307 (1982); United States v.
Tennessee, No. 92-2062, slip op. (W.D. Tenn. Feb. 17, 1994);
Halderman v. Pennhurst State School & Hospital, No. 874-1345,
slip op. (E.D. Pa. March 29, 1994); Jackson v. Fort Stanton Hosp.
& Training School, 757 F. Supp. 1243 (D.N.M. 1990), rev'd in part
on other grounds, 964 F.2d 980 (10th Cir. 1992); Thomas S. bv
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); Clark v.
Cohen, 613 F. Supp. 684 (E.D. Pa. 1985), aff'd, 794 F.2d 79 (3d
Cir. 1986) cert. denied, 479 U.S. 962 (1986); Garv W. v.
Louisiana, 437 F. Supp. 1209 (E.D. La. 1976).

and ensure critical medical needs are met. In sum, medical care for the most serious needs of the facility's residents is inadequate and fails to comport with generally accepted medical standards.

In addition, medication practices are deficient. There are numerous residents who have been prescribed multiple anticonvulsant and/or/psychotropic medications for years. view of the potential risks associated with many of these medications, including potential for toxicity, tardive dyskinesia, and reduced cognition, it is generally accepted by medical professionals that polypharmacy or the prescription of multiple medications should be avoided where possible. However, GVDC physicians continue to prescribe such medications absent any rational justification in violation of medical standards. Indeed, psychotropic medications are used on a routine basis at the facility absent adequate rationale or a psychiatric or neuropsychiatric diagnosis. The ubiquitous use of anticonvulsant and psychotropic medication also indicates inadequate consultation with neurologists and psychiatrists. These practices are unacceptable.

The absence of adequate participation of psychiatrists in the treatment of residents is particularly significant. For those dually diagnosed individuals who need both behavioral programming and medication for their mental illness, it is critical that both treatment modalities be integrated properly. The unavailability of adequate psychiatric consultation has severely impeded the ability of GVDC to address the needs of those residents. The inappropriate use of psychotropic medication is a direct result of this deficiency.

Quality control, peer review, and coordination mechanisms for medical care are virtually non-existent. The relationships between physicians and other personnel such as occupational therapists, physical therapists, psychologists, and nurses is ill-defined. Although GVDC's policies require that physicians order certain therapies, there is no mechanism to ensure that those needing the various therapies receive such orders. Medical staff meetings apparently take place only sporadically. There is no regular morning report among physicians and nurses, and no "on-call" or physician duty logs are regularly kept. Medical records are deficient in that important reports are misfiled and cannot be located. Progress notes are illegible as well. Such lapses in medical care delivery violate basic medical standards.

In the view of our consultants, most of these deficiencies can be attributed to the absence of adequately trained medical professionals, including physicians and nurses. The current physician staff is inadequately trained, organized and supervised to provide adequate medical care. Some of the physicians have little training or experience in working with developmentally.

disabled persons and few protocols have been developed to provide guidelines to the staff. For example, no protocols or procedures are in place on the subjects of tracking or managing emergencies, aspirations, weight loss or gain, dysphagia, or seizures. Policies regarding the frequency and tracking of tardive dyskinesia screenings and hepatitis vaccinations should be developed. Moreover, there has been little effort to provide medical staff with continuing education. The lack of trained medical staff has significantly compromised medical care at GVDC.

In sum, the medical care system at GVDC is seriously deficient. Serious illnesses are not addressed in a timely manner. Preventable illnesses, unnecessary injuries, and other debilitating conditions occur absent appropriate professional medical intervention.

B. Physical and Nutritional Management

Many residents at GVDC are nutritionally at risk due to physical disabilities or other medical problems and are not receiving appropriate assistance and training during meals. Failure to appropriately position residents during meals can lead to aspiration, choking, reflux and other health complications. Staff who assist residents at mealtime must receive special training in order to ensure residents' health and safety. Although we observed one meal at which residents were generally being fed appropriately, on many other occasions we observed residents eating in poor positions and the meal plans ("red cards") that were available were often either not followed or not appropriate for the particular resident for whom the plan was developed.

C. Physical Therapy and Positioning of Physically Handicapped Residents

Physical therapy services at GVDC are seriously deficient. One physical therapist for a population of over 600 residents, many of whom have physical disabilities and a related need for physical therapy services, does not allow the provision of adequate and appropriate physical therapy services. In fact, only 72 residents are currently receiving such services in spite of the large number of residents in the GVDC population who require such services. Ill-trained physical therapy technicians fail to fill the void left by the lack of an adequate number of physical therapists.

Moreover, our physical therapy consultant identified a significant number of dangerous practices being conducted by those few individuals actually engaged in physical therapy activities. For example, technicians routinely failed to take simple precautions such as locking wheelchairs from which residents were transferred to a position for walking. Review of

incident reports shows that approximately 13 percent of the injuries reported resulted from inappropriate handling of residents during transfer or in use of their wheelchair. No technician ostensibly providing physical therapy was observed endeavoring to teach residents any skills. Technicians used the same walker for multiple residents with broad differences in gait and height. Indeed, deficiencies in addressing the needs of residents with physical disabilities, especially children, are so severe as to represent an active threat to their health and safety.

Appropriate positioning for residents who have multiple physical disabilities is necessary to prevent deterioration of residents' skills, abilities, and health. Our physical therapy consultant made numerous observations of inadequately and improperly positioned residents. Many residents were observed in wheelchairs which did not adequately support them. All sling seat and sling back chairs observed were inappropriate. Chairs were also not appropriately designed and constructed to manage scoliosis and other spinal malalignments. Other chairs were simply too small for the residents using them. Physically disabled residents not in wheelchairs were likewise observed to be placed consistently in inappropriate positions.

Furthermore, accurate and useful documentation of an individual's physical therapy status does not exist, making it impossible to evaluate whether any intervention was effective, ineffective or in need of modification. In fact, many residents reviewed were continued for years on the same programs with little or no progress noted, which would require a modification or at least a re-evaluation of the therapy provided.

In sum, physical therapy services, including the positioning of residents, are so deficient as to represent a direct threat of harm to residents.

II. Residents of GVDC Are Not Adequately Protected From Harm or the Serious Risks of Harm Due to Lack of Supervision.

Direct care staffing is so deficient that many GVDC residents are harmed and are at substantial risk of harm because of the lack of adequate numbers of competent and qualified staff. Our observations and review of documents reveal that numerous injuries occur to residents which staff do not observe as they happen or do observe and fail to prevent. Residents are repeatedly "found with blood" on them from injuries that occur outside of staff supervision. On other occasions, residents' severe injuries are discovered only during bathing or at bedtime. In such instances, the staff report that they are unaware of the cause of the injuries. Such a high degree of unexplained injuries is unacceptable.

Some residents at GVDC repeatedly engage in self-abusive and other self-injurious behavior, such as serious head slapping or gouging their wounds. For instance, one eleven year old boy apparently lost the sight in one eye from repeated headslapping which resulted in a detached retina. Other residents were noted with swollen, disfigured features resulting from years of self-injury. Still others had permanent scars from continual self-mutilation of their faces and arms.

Incident reports detail a variety of unexplained and serious incidents and injuries at GVDC. Although not all accidents can be prevented, many of the injuries suffered by GVDC residents are preventable products of inadequate staff supervision or intervention. 2/

Over one third of the injuries reported in incident reports -- lacerations, fractures and bruises -- result from residents' behaviors, including self-injury and aggression. Many of these incident/injury reports concluded with the notation that the injury was "unavoidable due to resident's behavior," reflecting the facility's lack of confidence in either the residents' ability to learn alternative behaviors or in the facility's capacity to provide appropriate supervision and training. The most frequent recommended response to these incidents is for staff to engage in closer supervision. Such supervision is impossible given current staffing levels.

The number of unexplained injuries reflected in the incident reports is particularly disturbing because staff reported that minor injuries of unknown cause are intentionally not reported. As such, the reported injuries do not reflect the entire range of injuries of unknown origin. Out of a sample of ten residents observed during the tour as exhibiting recent notable injuries, 60 percent of the residents had injuries for which no incident report could be located. Several other reports contained descriptions of injuries that did not accurately reflect the injury observed.

In sum, there is an unacceptable level of injury at GVDC. The level of injuries of unknown origin is also greatly disturbing.

^{2/} Approximately 40 percent of incident/injury reports reviewed showed an injury due to falls. Such injuries can be divided into falls due to seizure activity, falls due to gait or instability problems, particularly in cramped areas, or aggression by other residents. While some seizure-related falls may be difficult to prevent, GVDC is aware of residents whose gait or behavior problems contribute to their falls and should be able to prevent many more of those injuries.

III. Programs to Reduce Maladaptive Behavior and to Provide Adaptive Skills Are Inadequate or Non-existent, Subjecting Residents to Physical and Mental Harm.

Deficiencies in the program services at GVDC, including both programs designed to eliminate maladaptive and other anti-social behaviors as well as programs to teach residents adaptive and other skills, are significant. Indeed, the deficiencies are so severe that the absence of necessary programs subjects residents to harm and unreasonable risks of harm. Furthermore, services do not provide residents with the necessary skills to enhance their independence or promote and maintain residents' physical and mental health.

A. Psychology Staff is Inadequate to Provide Necessary Services

GVDC currently has two doctoral level psychologists and eight masters level "psychological examiners." Psychological examiners are responsible for yearly evaluations of residents and the design and follow-up of individual behavior programs, including the training of direct care staff in the implementation of all programs. At present, each psychological examiner has a caseload of between 80 and 90 residents -- far too many. In addition, supervision of the psychological examiners by the Ph.D. psychologists is inadequate. At present, there is insufficient professional expertise available at GVDC to develop and implement adequate training and behavior management programs.

B. Behavior Programs Are Not Adequately Designed or Implemented to Train Residents With Maladaptive Behaviors

Significantly, many residents who need behavior programs do not have such programs. Their destructive behaviors remain unaddressed. For example, one resident had large scratches on her face that had been self-inflicted; our consultant psychologist was informed that there was no program to modify or eliminate this unsafe behavior. Staff described the wound on the forehead of another resident as a wound that the resident frequently re-opens; there was no program to correct this behavior and our consultant was advised that staff "just leave it alone." An older gentleman who had a history of pica (eating foreign objects) documented in his record dating back to 1977 was observed eating artificial grass and hitting his face; there is no program to correct these behaviors. The failure of professional staff to develop and implement behavior programs to address these and other dangerous behaviors represents a clear danger to residents, and is unacceptable.

Those behavior programs in place at GVDC, known as "goal plans," fail to comport with generally accepted professional standards in that they are not designed to accomplish changes in

residents' behavior or functional ability. Few of the goal plans are accompanied by a professionally based functional analysis of the resident's behavior -- a necessary first step in the development of a behavior program. Absent an adequate assessment, an adequate behavior program cannot be developed.

In addition, the behavior programs at GVDC are not individualized to meet the needs of the particular residents for whom they have been developed. Moreover, although staff reported that all behavior programs and skill acquisition programs are modified in the absence of progress, a review of records reflected many programs which had not been modified where no progress had been shown for protracted periods of time. Our consultant also determined that the lack of reliable data on residents' adaptive and behavioral programs seriously compromised the facility's training programs. Finally, direct care staff have not been adequately trained to implement training programs or to address the self-injurious behavior exhibited by many residents.

C. Adaptive Skills Training is Inadequate

Similar deficiencies also exist in the programs for the development of functional or adaptive skills. Training programs should focus on the acquisition of functional skills across a range of settings, people, and target behaviors. Training such as that at GVDC, which is often related to meaningless or isolated skills, does not enable the individual to acquire control over his/her environment, affect the individual's quality of life, or promote independence. Communication skills in particular should receive much more emphasis than is currently provided at GVDC and should be integrated throughout the residents' activities. While some of the communication boards and devices were excellent, many individuals who needed such devices did not have them. Our observation revealed few instances where opportunity to work on communication skills was presented to the residents and even where such skills were being presented, the training was not individualized to the residents involved. For example, a staff person was attempting to teach residents with no verbal skills the word "fork" without either a picture board or an attempt to teach a sign. Also, while a toilet training team has been developed at GVDC, many residents who could benefit from such training do not receive it.

A significant factor to the ineffectiveness of the programming at GVDC is the utter lack of reliable data being collected on residents' adaptive and behavioral programs. During an entire week on-site at GVDC, we observed data being collected on only two occasions. The lack of reliable data makes it impossible to determine the efficacy of programs and forces the residents to lose valuable training time by remaining in ineffective programming.

The inadequacies in the development and implementation of behavioral and other training programs at GVDC exacerbates self-injurious behaviors, leads to needless injury, and otherwise harms the physical and mental health of residents.

D. Individual With Disabilities Education Act (IDEA)

The school-aged children at the facility fail to receive a free and appropriate public school education as required by the IDEA and its implementing regulations. The IDEA requires that children with disabilities be educated with children who are non-disabled "to the maximum extent appropriate." The Individual Education Plans (IEPs) at GVDC do not reflect the need for the children who are not educated in the public schools to remain at the institution for educational services. The provision of services for students aged 14-21 in a local elementary school is not an appropriate placement for those individuals. Moreover, physical therapy and other services related to the provision of special education also fall far below accepted professional practices. Physical therapy interventions which directly relate to the goals of students' individual education plans are not integrated into each student's classroom activities. Communication skills are not effectively addressed in current individualized habilitation plans (IHPs) and IEPs. Opportunities for training are also limited inappropriately in that objectives are written to require only limited trials of any particular skill. In addition, many objectives do not appear to have a functional purpose for the individual student.

We note that most states have for many years declined to institutionalize children because institutional environments repeatedly have been demonstrated to be harmful to the full emotional, physical, and intellectual development of developmentally disabled children. Such harm is particularly acute in a facility like GVDC where conditions consistently fail to meet legal and professional standards.

IV. GVDC's Institutional Environment 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, development, and their overall well-being. Such environments must be functional and serve to enhance the quality of life for the individuals. Currently accepted professional standards require that this environment be the least separate, most integrated setting where the individuals needs can be met. It must be safe, stable, and operate to teach and maintain functional skills, to reduce or pre-empt the occurrence of behavior problems, and otherwise promote the independent

functioning of the individual. GVDC meets none of these requirements.

The environment at GVDC is not fully functional for its residents and may be the cause of some of their problem behaviors. Ironically, it is the presence of these behavior problems, the regression in skills experienced by many residents as the result of inadequate care, and the acuity of their physical disabilities produced by other inadequate services that decreases or delays the individuals' opportunity to live in and participate in community-based programs.

GVDC 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, enables independent functioning, and facilitates contact with family members. While some few residents enjoy frequent community outings, many others have very few opportunities to participate in community activities and still others apparently never leave the institution at all. 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. By confining residents with disabilities at GVDC, the State has failed to provide such services in the least separate, most integrated setting as required by the Americans with Disabilities Act of 1990, 42 U.S.C. § 12101, et seg., and section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, et seq.

The cases reviewed by our consultants indicate that all, or nearly all, of GVDC residents could be successfully placed in the community if provided with adequate supports. This view is not disputed by the professionals at GVDC. Keeping individuals in an institution who have been determined to be capable of living in the community cannot be justified.

V. Remedial Measures

In order to remedy these deficiencies and ensure that the rights of GVDC residents are protected, the following remedial measures need to be implemented promptly.

a. Hire, train and deploy adequate numbers of competent and qualified medical care staff, including physicians and nurses, to

meet the medical needs of the residents. Provide enhanced training opportunities to the present physician staff to teach them skills necessary to care for physically disabled, developmentally disabled persons. Increase the number of hours of consulting and contract professionals, especially those for neurology and psychiatry, to a level sufficient to provide adequate care. Arrange for a physiatrist to provide regular consultation. Ensure that enough adequately trained medical professionals, including nurses and pharmacists, are employed to institute appropriate quality assurance mechanisms, especially to oversee the prescription, administration, and monitoring of psychotropic and anticonvulsant medications, and to provide timely prevention, treatment and follow-up of medical problems.

- b. Provide adequate and timely medical care, including appropriate services to meet the acute, chronic and emergency medical care needs of residents. Ensure that physicians are immediately available to GVDC residents at night and on weekends. Develop and implement procedures and protocols for tracking sentinel health events and managing acute and chronic illnesses.
- c. Residents on psychotropic or anticonvulsant medications should be evaluated to determine the appropriateness of their prescriptions and whether these medications are being prescribed and monitored in accordance with accepted professional standards. Psychotropic medications must not be used without an adequate rationale and a psychiatric or neuropsychiatric diagnosis, nor as punishment, in lieu of a training program for behavior control, nor for the convenience of staff. Residents must not be kept on anticonvulsant medications (or inappropriate doses of those medications) that serve no therapeutic purpose or are otherwise contraindicated. The practice of using standing "PRN" orders for potent medications such as Ativan should be discontinued.
- d. Medical records must be kept in a fashion sufficient to allow medical professionals to provide adequate and timely care. Regular communication among medical staff must be established and enhanced. An adequate system must be developed for tracking and monitoring seizure disorders, and medical staff, as well as direct care staff, should be adequately trained in seizure management.
- e. GVDC must hire, deploy and train sufficient numbers of specialty service providers, including qualified physical therapists, physical therapy technicians, occupational therapists occupational therapy assistants, and speech pathologists, to ensure that residents are provided appropriate physical and occupational therapy, including positioning, the use of adaptive devices, eating, and ambulation, and other functional skills training, including communication skills.

- f. GVDC must employ and deploy sufficient numbers of competent and trained professional and direct care staff to ensure residents are supervised and adequately protected from harm and provided appropriate training and other services.
- g. All residents must be evaluated to determine their individual strengths and weaknesses and to develop appropriate individualized training programs, including behavior management and skill acquisition programs. 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. All interdisciplinary evaluations should review the individual's training needs, utilizing a written descriptive functional analysis for those individuals with problem behaviors, and emphasize alternatives to restraints. Programs should address and develop appropriate strategies to promote the physical, mental, behavioral, and social skills of each resident and permit each resident to function as independently as possible. Such programs must be consistently implemented and procedures developed to ensure appropriate review and revision.
- h. GVDC must develop and implement a professionally based, individually appropriate data collection system to measure relevant information about problem behaviors and the conditions under which they occur, including, where appropriate, the frequency, intensity, and duration of the behaviors. GVDC must implement an appropriate data collection system to ensure that adaptive and functional skills training is meeting the needs of the resident involved. Furthermore, GVDC must review and respond to the data collected relating to either behavior programs or skill acquisition programs in a timely and appropriate manner.
- i. GVDC must ensure that each school-aged resident is evaluated and provided educational services, included related aids and services, consistent with the requirements of IDEA. Evaluations should be coordinated with the appropriate public school district to ensure that each child receives educational services in the least restrictive, most appropriate, environment outside GVDC. IEPs must be suitably individualized and contain functional objectives.
- j. Immediate steps must be taken to develop and implement an overall plan to significantly reduce the size of the facility and to place residents in appropriate, less restrictive, community-based programs. There should be an immediate ban on the admission of children, except in emergency circumstances, and children should be prioritized for placement in alternate, properly supported community-based programs. In the meantime, residents should receive training to assist in their placement and transition to community-based living arrangements. Residents

should also be adequately assessed to identify services necessary to meet their needs in the community.

Large, congregate residential institutions have been demonstrated to be ill-equipped to provide the care, education, and training needed to promote the growth and development of developmentally disabled and mentally retarded persons. See, e.g., Halderman v. Pennhurst State School & Hospital, No. 74-1345, slip op. at 1, 4-9 (E.D. Pa. March 29, 1994). The national trend is to serve these individuals in appropriate, alternative community-based programs and facilities which can meet their individual needs. Given the gravity and scope of our experts' findings regarding the deficient care provided at GVDC, the development of more appropriate settings and services for the residents of GVDC is necessary.

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cc: The Honorable Charles W. Burson
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