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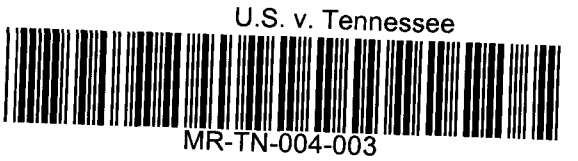


The Honorable Don Sundquist
Governor
State of Tennessee
State Capitol
Nashville, Tennessee 37219

Re: Clover Bottom Developmental Center

Dear Governor Sundquist:

On June 23, 1994, we advised Governor McWherter of this Department's intent to investigate conditions at the Clover Bottom Developmental Center ("CBDC") in Nashville, Tennessee, pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. During the weeks of September 26, October 3, and October 10, 1994, we toured the facility accompanied by consultants in the fields of medicine, psychology, psychiatry, nursing and physical therapy. We want to thank the CBDC staff and the representatives from the Department of Mental Health and Mental Retardation and the Attorney General's office for their cooperation during this investigation. Following each of our tours, we conveyed to the facility superintendent and other state officials an initial assessment of deficiencies at the facility. Although we have not yet finished our assessment of the Harold Jordan Center, we have completed our findings with regard to CBDC itself.

We regret to advise you that we found numerous conditions at CBDC 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/ CBDC is not in compliance with the Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101, et seq., Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, the substantive provisions of Title XIX of the Social Security Act, 42 U.S.C. §§ 1396, et seq., and the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §§ 1400, et seq. Our review also indicates that the rights of the residents guaranteed by Tennessee state law are also being violated. See, e.g., Tenn. Code Ann. § 33-3-104 and § 33-5-201.

The general facts that support our findings of unconstitutional conditions and violations of federal statutory rights at CBDC are set forth below.

I. CBDC Residents Are Not Adequately Protected From Harm or Serious Risk of Harm Due to the Lack of Supervision and Programming.

The most serious and pervasive health risk to the residents of CBDC is that of injury. Fractures, lacerations, and soft tissue injuries are documented repeatedly in the records and were obvious to our experts as they toured the living units. The lack of adequate direct care staff, the almost total lack of unit activities or stimulation of any kind, and the inability of staff to manage maladaptive or aggressive behaviors, were apparent throughout the tours and undoubtedly contribute to the high rate of injuries suffered at CBDC. Residents with sensory impairment are even further isolated by the lack of attention to their needs. Furthermore, CBDC's investigation and analysis of injuries is not calculated to reduce or eliminate injuries or abuse of residents by staff.

1/ 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; Title XIX of the Social Security Act, 42 U.S.C. §§ 1396, et seq. (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. 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); 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); Gary W. v. Louisiana, 437 F. Supp. 1209 (E.D. La. 1976).

A. Injuries

Many of the injuries suffered by CBDC residents may be related to the dearth of appropriately trained and supervised direct care staff. Document review and observations confirmed that CBDC residents suffer from the chronic under-staffing at the facility. Furthermore, it became apparent that many staff did not have, or were not being required to utilize, the necessary skills to serve developmentally disabled persons. Many injuries occurred, as reported in incident reports, in which the staff person's description of the event indicated that sufficient time existed for staff intervention, but such intervention did not occur. For example, one resident hit another two separate times and after the second assault, the attacked resident retaliated by biting the first resident all over his chest. While this course of events was recorded, it was not interrupted.

CBDC's insufficient staffing results in staff not familiar with residents often working in units other than where actually assigned. Many staff interviewed during our tours were unable to identify the individuals for whom they were providing care and other staff freely admitted that they were not working in a unit where they usually worked. Lack of familiarity with the individuals living in various units creates difficulties for even the best-intentioned staff, who may be unaware of significant issues in their temporarily assigned unit.

While many of the incident reports described injuries that were obviously observed by staff, many other injuries were found only after they had occurred. Such unobserved injuries include serious lacerations, bruises and sprains.

Furthermore, the incident reporting system that CBDC uses does not allow for the kind of analysis that would enable the facility to prevent re-occurrence of avoidable injuries. For instance, in one eight month period, one resident received lacerations serious enough to require stitches on seven separate occasions. For five of those incidents, the injury was described as the result of another resident, unidentified in each instance, pushing or hitting the injured resident. One laceration was of unknown origin and the last was reported to be self-inflicted, apparently by accident. Without more information in the reports, it is impossible to tell whether or not the same resident was responsible for the five assaults. That information is significant for CBDC to analyze in order to prevent future altercations.

In another instance, the incident reports reveal that in one seven month period, a resident received injuries on twenty-six occasions. Many of those injuries were reported to have occurred during fights with other residents, one-third were reported as self-inflicted, several were found on the resident (of unknown

cause) and one was caused when the resident was being restrained. Half of the injuries were serious enough to require stitches and in one instance the resident lost two teeth. Significantly, several of the incident reports noted the re-opening of earlier wounds that were not represented in earlier incident reports. Therefore, the injury reports summarized here under-represent the true extent of the injuries suffered by this resident. This inaccurate recording extends beyond just this one individual. During our tours, we observed many other residents with injuries for whom no incident report describing that injury could be found. We, therefore, conclude that the documentation of injuries, as the documentation in all other areas, was not complete and that the injuries described in CBDC incident reports do not represent the totality of injuries actually experienced by CBDC residents.

The examples of injuries described above are not isolated, exceptional circumstances, nor the most egregious. Our review of injury documentation and our observations during the tours reveal that CBDC residents suffer injuries and assaults on a regular basis and are at serious risk of harm in their own living units and throughout CBDC.

B. Abuse and Neglect

CBDC does not adequately protect residents from physical and verbal abuse and neglect. While there is a system established to investigate allegations of abuse, we note that the investigations appear to be cursory and typically fail to substantiate abuse allegations even in cases where evidence suggests abuse occurred. Although a number of the abuse investigations we reviewed began when an injury of unknown origin was found on a resident, the incident/injury reports document many more such injuries that were not likewise investigated. There is no way to determine from the documentation why one injury of unknown origin is considered suspected abuse and another is not. Furthermore, given the inadequacies of the incident documentation outlined above, many potential incidents of abuse are never investigated.

Verbal abuse appears prevalent at CBDC. Direct care staff either have not been adequately trained to interact with residents in appropriate ways or have not been adequately supervised. During our tours, we rarely heard a direct care staff person actually provide praise or positive reinforcement while interacting with residents. Many staff did not even speak to the residents for whom they were caring, even while doing such tasks as feeding the resident or taking the resident to be bathed. Abrupt, verbal commands such as "SIT DOWN!" and "STOP!" appear to be the too frequent method by which staff communicate with residents. A number of residents' behavior plans actually instruct direct care staff to use those commands, and it was reported that staff often scream at residents to comply.

The obvious staffing difficulties contribute to the neglect of residents who may be left for extended period of time in soiled clothes or engaging in self-injurious behavior unattended.

Finally, there is evidence that staff are not encouraged to report abuse or neglect and that some staff are intimidated by other staff from reporting such incidents.

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

CBDC does not provide residents with basic, functional, and progressive programming designed to reduce injuries, improve resident living skills, eliminate maladaptive and other antisocial behaviors, reduce the amount of supervision that they require, prepare them for living in the community, or meet the specific individual needs of the residents. Consequently, residents are at greater risk for injury (e.g., from aggression or self-injury), are more likely to remain institutionalized, are more likely to receive physical or chemical restraints, and more likely to receive medication to control their behavior than might otherwise be necessary. In sum, the programming and psychological services at CBDC are so deficient as to subject residents to serious and continuing harm and risks of harm.

A. Psychology and Direct Care Staff

CBDC currently has one doctoral level psychologist, who is the Director of Psychology, and ten 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. Given the insufficient training of psychology and direct care staff, the inappropriate environment at CBDC and the number of residents presently exhibiting maladaptive behaviors, the caseload of each psychological examiner (between 65 and 120 residents) is far too high. Psychology staff are overworked, have no authority, little or no professional/clinical support, inadequate training, no professional/career development, and no expert Ph.D. involvement. At present, there is insufficient professional expertise available at CBDC to develop and implement adequate training and behavior management programs. In addition, direct care staff, who are primarily responsible for implementing the programs and training, are insufficient in number and inadequately trained to properly carry out appropriate programming and training.

B. Behavior Programs and Training for Residents With Maladaptive Behaviors

CBDC residents with maladaptive and self-injurious behavior continue to suffer unnecessary injury and restraint, in large part because of CBDC's inadequate behavior programming for these individuals. The necessary precursors to designing adequate behavior programs are proper assessments and functional behavior analyses of the individuals requiring such programs. CBDC does not conduct proper assessments necessary to design effective programs. For example, most of the residents at CBDC have severe communication and language deficits. Improving a person's ability to communicate is important in reducing the occurrence of maladaptive behaviors, developing social relationships, and increasing control over one's own environment. Communication assessments at CBDC provide little useful information and recommendations. In addition, our psychology consultant found no evidence that functional behavior analyses have been conducted for any resident.

The programs themselves, while generally covering the appropriate subject areas, are not individualized for each resident (in some cases the programs are virtually identical), are incomplete in necessary details, contain objectives that do not make up a comprehensive, sensible plan, and are not implemented. Our consultant also determined that the lack of reliable data on residents' adaptive and behavioral programs seriously compromises the facility's training programs. Data recorded on many of the behavior and skill data sheets are identical from day to day, giving the appearance that data is fabricated or recorded at the end of the day, week, or even month, making such data meaningless. Finally, direct care staff have not been adequately trained to implement training programs or to address the self-injurious behavior exhibited by many residents. The emergency physical restraint practiced at CBDC is an inherently risky procedure which puts residents at serious risk of harm or even death. In short, CBDC residents are not being helped, but are allowed to continue harming themselves, peers and sometimes staff day after day, year after year.

Some of these deficiencies at CBDC are illustrated by the events surrounding a recent study conducted by researchers from Vanderbilt University at CBDC to examine the effects of the medication, Naltrexone, upon self-injurious behavior. Although the researchers found that the seven CBDC participants would not or could not benefit from the medication, they made a number of clinical recommendations for at least some of the participants. These recommendations were comprehensive, addressed the function of the self-injury, and applied the latest research in mental retardation to the individual resident. None of these recommendations, however, appear to have been followed

by CBDC and, moreover, none of the staff members with whom our consultant spoke knew anything about the study or the recommendations. This is an example of CBDC's inability to apply important relevant assessment information for the benefit of the residents. Information which could very well have helped these individuals and prevented further injury and restraint was made available, but was ignored.

C. Adaptive Skills Training

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 CBDC, which is often related to meaningless or isolated skills, does not enable the individual to acquire control over his/her environment, enhance the individual's quality of life, or promote independence. Staff members do not appear to know how to teach skill development to this population and, in the few cases where they were trying to teach, they were operating under conditions that made it nearly impossible to be effective (e.g., supervising many residents simultaneously, inadequate materials available).

Little communication and language training is conducted at CBDC. Records indicate that only 12 residents have any kind of adapted/augmented communication device. Communication skills must receive much more emphasis and should be integrated throughout the residents' activities. Our observations revealed few instances where opportunities to work on communication skills were presented to the residents and even where such opportunities were being presented, the training was not individualized to the residents involved.

All of our consultants were shocked at the general lack of activity at CBDC. For example, our psychology consultant's observations of 18 different living units and training areas primarily during daylight hours revealed that only 26 to 36 percent of the residents were engaged in any activity. The vast majority of residents were observed sitting doing nothing, lying down or sleeping. Resident activity schedules contain large blocks of time labeled, for example, "watch TV," "radio," "table activity," "leisure," "self-help," or "given opportunity to participate in preferred activities" -- all prescriptions for sitting and doing nothing. Staff also did not appear to follow the schedules. Similarly, few appropriate supplies were available for teaching new skills, for leisure time, or for increasing engagement. Many of the materials were broken, missing pieces, or age inappropriate.

The residents' boredom from the lack of meaningful or interesting activities, the lack of adequate staff, and the

inadequacies in the development and implementation of behavioral and other training programs at CBDC exacerbate self-injurious behaviors, lead to needless injury, and otherwise harm the physical and mental health of residents.

D. Individual With Disabilities Education Act (IDEA)

CBDC is not providing its school-age residents with an appropriate education in accordance with the requirements of the Individual with Disabilities Education Act (IDEA), 20 U.S.C. §§ 1400-1486. The IDEA requires that CBDC develop individualized education plans (IEPs) designed to meet the needs of qualifying children. A review of IEPs developed for children at CBDC showed that they failed to meet this standard. The goals and objectives in the IEPs were extremely limited in their scope. For example, it was common to find only two skills being addressed over a three-year period.

Further, the IDEA's requirement that sufficient "related services," i.e., physical therapy and behavioral services, be provided to allow children to benefit from the educational program is clearly not being met. For example, the physical therapy staff do not interact at all with the educational staff. In addition, children attending the CBDC school could be educated in lesser restrictive environments; also a requirement of the IDEA. CBDC must enhance its educational and related services and provide for appropriate placement and services in the local public school systems.

III. Medical and Psychiatric Care is Dangerously Deficient.

A. General Medical Care

The medical care received by the residents at CBDC is dangerously deficient. Although our consultants reviewed individual instances of appropriate care, medical care generally is characterized by "crisis management," with numerous individuals suffering unnecessary pain, injuries and illnesses. The primary cause of this is the grossly inadequate numbers of trained medical personnel presently employed at CBDC. At the time of our tours, the facility had just hired one additional full-time physician, bringing the total number of physicians to three, which included the acting medical director. In the opinion of the acting medical director, adequate medical care could be provided with five full time physicians and one medical director. This would require hiring three more physicians. Similarly, nursing coverage is woefully inadequate to meet the needs of the residents. According to the CBDC "Resource Plan," the facility would require an additional forty-one Registered Nurses and fifty-nine Licensed Practical Nurses, just to meet the staffing ratio established by the Department of Mental Retardation.

Moreover, as a general rule, CBDC medical personnel do not have significant experience caring for individuals with developmental disabilities prior to employment at CBDC, and they receive insufficient orientation before starting work and practically no continuing education once they begin work.

This inadequate staffing, coupled with inadequate experience and training, has the greatest impact on the quality of preventive and chronic care. Records at CBDC, as at the Greene Valley Developmental Center, demonstrate that CBDC residents are subjected to 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; inadequate medication administration; and other misdiagnosed or untreated injuries. Our medical consultants were also struck by the number of serious cases of skin breakdown or decubitus ulcers, which generally indicates that there are too few adequately trained staff to track residents who are at risk for such ulcers and to ensure residents receive good hygiene and are repositioned frequently.

Seizure management is also deficient. In several cases the advice of the consulting neurologist was excellent and the advice was followed by CBDC physicians. However, the charts of a number of other residents indicated that they had not been seen by a neurologist for years, had been maintained on anticonvulsant medications despite having no seizures for years, or had been maintained on grossly subtherapeutic doses of anticonvulsants for many months and sometimes more than a year. Our medical expert found one case where intra-muscular medication was inappropriately used to treat a seizure. In addition, the inconsistent recording of seizures by CBDC staff seriously affects the legitimacy and efficacy of prescribed medications and treatment.

In one representative case, a 48-year-old woman who died in October 1993, was started on an anticonvulsant after having a seizure in the spring of 1993. Lab tests taken over the next seven months showed repeated, substantially subtherapeutic levels of the medication in her blood, despite at least two more seizures. One of the seizures, lasting ten minutes and described as "uncontrolled," prompted the neurologist to recommend increasing the dosage of the anticonvulsant, but the blood level remained subtherapeutic for the next several weeks until her death. (The consultant also noted that this resident had a 70 pound weight loss, but the primary care physician's note from the previous month had not remarked on this weight loss and had stated only that the patient was "doing well.") The woman had another prolonged seizure, was sent to the hospital, and died the

next day, probably as a result of aspiration during her prolonged seizure. In this case, therapeutic drug levels were not actively pursued by the primary care physician in the face of increasing seizure activity. The resident's dramatic weight loss was also not acted upon.

Emergency care at CBDC is also inadequate. CBDC has no written guidelines as to when 911 should be called. Transportation of residents, who are or may be in need of immediate emergency medical care, from their living units to the medical building by non-medical personnel, such as security officers, is generally not appropriate. Seriously ill or injured residents should be attended and accompanied by trained medical personnel. Residents who are in need of immediate emergency care should be transported from their living units by EMTs directly to the hospital.

Quality control, peer review, and coordination mechanisms for medical care are virtually non-existent. Medical recordkeeping and data collection are also inadequate. Individual medical records are often in disarray, important information is missing, progress notes and plans are cursory, documents are misfiled and important physician notes are illegible. Although CBDC has begun to keep lists of individuals at risk for various ailments, it is clear that there is a general absence of individual or facility-wide data with respect to chronic medical needs of residents. This absence of information collection not only compromises the care of individual residents, but limits the ability of the medical staff and administration to properly allocate resources, develop plans, and ensure critical medical needs are met. Our expert consultants found repeated instances, for example, where residents' conditions or risks were noted, but no plan was in place or implemented to correct those conditions or reduce the risks. In cases where data is kept, it does not appear to be utilized in any useful fashion.

In sum, medical care for the most serious needs of the facility's residents is inadequate. Serious illnesses are not addressed in a timely manner. Preventable illnesses, unnecessary injuries, and other debilitating conditions occur absent appropriate professional medical intervention.

B. Psychiatric Care and the Use of Psychotropic Medication

Psychiatric services for CBDC are seriously deficient. This is due in large part to the inadequate number of psychiatric consultation hours available at the facility. The current consulting psychiatrist spends only seven to ten hours a month at CBDC even though over 100 CBDC residents are receiving medications that require psychiatric supervision. This is simply inadequate given the potential effects and side effects of the psycho-active medications to which CBDC residents are exposed.

As mentioned above, CBDC's behavioral treatment system is grossly inadequate. In the face of an ineffective behavioral treatment system, the use of medication to control residents' behavior becomes even more problematic. It is essential that, before medications are used on residents, alternative, less-intrusive behavioral therapies are tried and proven to be unsuccessful. However, at CBDC, adequate behavioral therapies are not in place. Thus, medication used to control behavior becomes, per se, an inappropriate use of chemical restraint.

Further deficiencies also exist in the practices in use at CBDC concerning behavior-modifying medications. The extensive use of benzodiazapines, which have a high percentage of negative side effects in a developmentally disabled population, is not being adequately monitored. Also, as noted above, behavior data, critical to the analysis of the efficacy of medication, is not appropriately collected, graphed or charted in residents' records. Further, staff members often present conflicting data to the psychiatrist when the psychiatrist performs consults. Without accurate and consistent behavioral data, the use of psycho-active medications is inappropriate.

Additionally, there is no formal, standardized process for approval of residents' medication regimens. Nor is there a physician on CBDC's Behavior Management or Human Rights Committees. Further, CBDC's procedures for tracking medication side-effects is deficient. In sum, the use of behavior control medications at CBDC is unacceptable, does not adequately address residents' needs and represents a danger to residents.

C. Physical and Nutritional Management

Physical and nutritional management at CBDC are deficient. Many CBDC residents, like some of the residents at Greene Valley Developmental Center, are nutritionally at risk due to physical disabilities or other medical problems and are not receiving appropriate assistance and training during meals. Staff who assist residents at mealtime must receive special training in order to ensure residents' health and safety. For example, failure to appropriately position residents during meals can lead to aspiration, choking, reflux and other health complications. Although CBDC documents note the importance of positioning and feeding residents properly during and after mealtimes, our consultants' observations revealed that staff were not doing so and residents were coughing and choking as a result. Several residents who are tube fed were also observed improperly positioned during and following the feedings. (None of the residents currently receiving gastronomy feeding have oral stimulation programs.) Although some residents have individual feeding plans or cardexes' designed to instruct staff on how to properly feed the residents, some residents in need of such plans do not have them, and many of the cardexes are cryptic or outdated.

CBDC also fails to appropriately identify and treat individuals with unhealthy weight loss, eating disorders, dysphagia or reflux; all of which, if untreated, can become fatal conditions.

D. Physical Therapy and Positioning of Physically Handicapped Residents

Physical therapy services at CBDC are seriously deficient. Direct care and professional staff generally are untrained in how to properly position, transfer or move residents. There is ineffective implementation of the individualized habilitation plan ("IHP") by staff from all services, and functional integration of this plan is lacking. As in other areas, objective data necessary to establish goals and measure progress is generally absent. There is a need for more physical therapy services for patient evaluation, program development, and supervision of program implementation. Additional registered physical therapists need to be hired.

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 lifted or moved residents by grabbing and pulling on their arms or legs -- which can easily result in broken bones for some of these medically fragile individuals. Staff also failed to take simple precautions such as locking wheelchairs before transferring residents in or out of the chairs.

In other cases, residents were inappropriately placed or allowed to remain in devices or postures which inhibited their ability to function, and, in some cases, may exacerbate their deformities. Many of the adaptive wheelchairs and related equipment are ill-fitting and inappropriate. Few of the nonambulatory individuals were observed to wear shoes. This places them at risk for injury while in their chairs, especially because many of them did not have proper foot rests and their feet were observed to drag along the floor as they were moved in their wheelchairs. 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. Residents languish in carts and ill-fitting wheelchairs, which exacerbate or allow physical deformities to progress -- in some cases to a point that the deformity may preclude the person from sitting upright in a wheelchair. This seriously diminishes a person's opportunities for socialization and sensory input. Such inappropriate positioning can, among other things, constrict the lungs, cause

secondary lung disease, make it difficult for the heart to pump, and increase the likelihood of vomiting, reflux and aspiration.

Furthermore, accurate and useful documentation of CBDC residents' individual 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. Such lack of progress should prompt 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. An acceptable physical therapy program must enhance the capacity of the individual to function, i.e., to help him or her live safely and as independently as possible. Sporadic passive range of motion "therapy" is not sufficient to achieve these goals.

IV. CBDC'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. CBDC does not meet these requirements.

The environment at CBDC 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.

CBDC fails to appropriately provide for and monitor the residents' personal property or to protect it from theft. This disregard for residents' personal possessions is reflective of an environment that devalues the people who are confined at CBDC.

CBDC is an isolated, self-contained environment which 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 a 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. Data for the fourteen months prior to our tours demonstrate that approximately 40 residents never took a community trip off grounds and many residents had fewer than six outings for the entire year. Data for the summer of 1994 showed that 191 residents never went off grounds for community or recreational outings during that time.

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 CBDC, 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 seq., and section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794.

The cases reviewed by our consultants indicate that all of CBDC residents could be successfully placed in the community if provided with adequate supports. The professionals at CBDC are in general agreement with this view. Keeping individuals in an institution who have been determined to be capable of living in the community cannot be justified.

In those few cases where residents have been placed out of the Center, CBDC documents and our discussions with CBDC staff indicate that essential transitional services and planning has not taken place. For example, a deinstitutionalization plan designating community placement was included in each IHP that our psychology consultant reviewed, but the IHPs themselves did not contain objectives or a plan for, or otherwise focus on, this long-term goal. In addition, CBDC physicians are not involved in discharge planning to the community, and are not asked to provide transfer notes or communicate with community-based physicians regarding the medical status and needs of their patients prior or subsequent to their transfer. Dumping residents into the

community without adequate planning, services or supports is equally unjustifiable.

V. Remedial Measures

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

a. CBDC must immediately 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. Measures must be taken to ensure the timely and accurate reporting of abuse and neglect, and the effective investigation and resolution of those reports.

b. 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. One-to-one staffing must be provided immediately for residents who are at risk of serious injury. 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. Emphasis should also be placed on teaching residents to communicate. Restraint procedures must be revaluated immediately and changes made to avoid resident injuries and death by choking or asphyxiation.

c. CBDC 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. CBDC must implement an appropriate data collection system to ensure that adaptive and functional skills training is meeting the needs of the resident involved. Furthermore, CBDC must review and respond to the data collected relating to either behavior programs or skill acquisition programs in a timely and appropriate manner.

d. Measures must be taken to improve the communication and language training provided to CBDC residents. Similarly, CBDC

must assess each resident's need for associated or adapted devices including communication devices, and provide these devices for those individuals in need of them. Measures must also be taken to improve physical and nutritional management, including assessing residents at risk for dysphagia, weight loss, eating disorders and reflux, implementing measures to reduce those risks and teaching staff.

e. For each resident, CBDC must reasonably provide for, allow the residents access to, and take steps to protect the resident's personal property.

f. CBDC 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 CBDC. IEPs must be suitably individualized and contain functional objectives.

g. CBDC must 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. CBDC must provide enhanced training opportunities to the present physician staff to teach them skills necessary to care for physically disabled, developmentally disabled persons. CBDC must increase the number of hours of consulting and contract professionals, especially those for psychiatry, to a level sufficient to provide adequate care. CBDC should arrange for a physiatrist to provide regular consultation. CBDC must 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.

h. CBDC must provide adequate and timely medical care, including appropriate services to meet the acute, chronic and emergency medical care needs of residents. CBDC must develop an adequate protocol for emergencies, which, among other things, limits the prior practice of transporting seriously ill or obviously injured or ill residents unaccompanied by trained medical personnel. CBDC must ensure that physicians are immediately available to CBDC residents at night and on weekends. Develop and implement procedures and protocols for tracking sentinel health events and managing acute and chronic illnesses. Measures should be taken to reduce incidents of skin breakdown or decubitus ulcers.

i. Residents on psychotropic and 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.

j. Medical records must be kept in a fashion sufficient to allow medical professionals to provide adequate and timely care. An up-to-date problem list specific to each resident should be maintained in each resident's chart. 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. A seizures protocol should be developed, which, among other things, describes the appropriate administration of anticonvulsants.

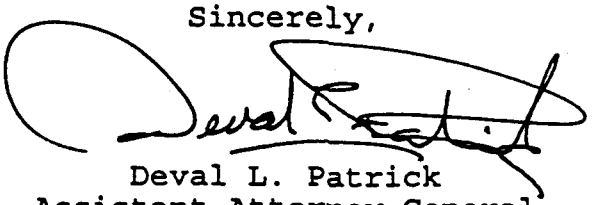
k. CBDC must hire, deploy and train sufficient numbers of specialty service providers, including qualified physical therapists, physical therapy technicians, occupational therapists occupational therapy assistants, and speech pathologists, to ensure that residents are provided appropriate physical and occupational therapy, including positioning, the use of adaptive devices, eating, and ambulation, and other functional skills training.

l. 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. CBDC staff must take a greater role in helping to ensure that residents' placements into the community are appropriate and successful.

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 CBDC, the development of more appropriate settings and services for the residents of CBDC is necessary.

Sincerely,



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