U. S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General *Washington, D.C. 20530*

November 12, 2004

The Honorable James E. McGreevey
Governor of New Jersey
The State House
P.O. Box 001
Trenton, NJ 08625

Re: CRIPA Investigation of the Woodbridge Developmental Center in Woodbridge, New Jersey

Dear Governor McGreevey:

I am writing to report the findings of the Civil Rights Division's investigation of conditions at New Jersey's Woodbridge Developmental Center. On April 8, 2003, we notified you of our intent to conduct an investigation of conditions and practices at Woodbridge, pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. CRIPA gives the Department of Justice authority to seek a remedy for a pattern or practice of conduct that violates the constitutional or federal statutory rights of residents with developmental disabilities who live in public institutions.

As part of our investigation, in June 2003, we conducted an on-site tour of Woodbridge with expert consultants in psychiatry, psychology, risk management, community placement, nutritional and physical management, and occupational and physical therapy. Before, during, and after our visit, we reviewed an extensive number of documents relating to the care and treatment of individuals residing at Woodbridge. We also interviewed administrators, staff, and residents, and observed conditions and practices at the facility. We conveyed our preliminary findings at exit conferences conducted at the conclusion of our tour.

As a threshold matter, we note that many Woodbridge staff are dedicated individuals who are genuinely concerned for the well-being of the persons in their care. Further, we would like to acknowledge and express our appreciation for the cooperation and assistance provided to us by Woodbridge administrators and staff throughout the investigation. In particular, we would like to thank Woodbridge's Director, John Dougherty, for his assistance and dedication.

Consistent with our statutory obligation under CRIPA, I now write to advise you formally of the findings of our investigation, the facts supporting them, and the minimal remedial steps that are necessary to remedy the deficiencies set forth below. As described more fully below, we conclude that certain conditions at Woodbridge violate the constitutional and federal statutory rights of the residents. In particular, we find that Woodbridge fails to: (1) protect residents from harm; (2) provide adequate behavioral services, freedom from restraint, and habilitation; and (3) provide adequate medical care. We further find that residents are not placed in the most integrated setting appropriate to meet their individualized needs. See Olmstead v. L.C., 527 U.S. 581 (1999); Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; 28 C.F.R. § 35.130(d).

I. BACKGROUND

Woodbridge is a State-owned and operated residential facility[1] serving individuals who have a variety of developmental disabilities, including mental retardation, cerebral palsy, autism, and spina bifida. At the time of our investigation, Woodbridge housed approximately 500 residents, ranging in age from 17 to 74 years. Many of Woodbridge's residents are medically complex, have ambulation issues, and require frequent monitoring and assistance with their daily needs. A number of residents also have swallowing disorders or seizure disorders.

II. FINDINGS

Individuals with developmental disabilities in a state institution have a Fourteenth Amendment due process right to reasonably safe conditions of confinement, freedom from unreasonable bodily restraints, reasonable protection from harm, and adequate food, shelter, clothing, and medical care. Youngberg v. Romeo, 457 U.S. 307 (1982); Clark v. Cohen, 794 F.2d 79, 87 (3d Cir. 1986). Accordingly, determining whether treatment is adequate focuses on whether institutional conditions substantially depart from generally accepted professional

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[1] Woodbridge is one of the facilities owned and operated by New Jersey that serve persons with developmental disabilities. As you know, we also investigated the New Lisbon Developmental Center pursuant to CRIPA, and the United States reached an agreement with the State of New Jersey regarding New Lisbon on August 2, 2004.

judgment, practices or standards. Youngberg, 457 U.S. at 323. Residents also have the right to be treated in the most integrated setting appropriate to meet their individualized needs. See Olmstead, 527 U.S. 581. As we describe in greater detail infra, however, we found that conditions and services at Woodbridge substantially depart from generally accepted professional standards of care.

A. PROTECTION FROM HARM

The residents of Woodbridge have a right to "conditions of reasonable care and safety." See Youngberg, 457 U.S. at 324. Although Woodbridge has taken positive first steps toward fulfilling its obligation to keep residents safe, by recently establishing an internal investigation unit and training staff on abuse and neglect, Woodbridge fails to provide the basic oversight of resident care and treatment that is critical to protecting the residents from harm and serious risks of harm. In order to maintain a reasonably safe environment for residents, applicable Medicaid regulations and generally accepted professional standards dictate that the facility must provide for adequate supervision by trained staff. See 42 C.F.R. § 483.420(a)(5) ("Ensure that clients are not subjected to physical, verbal, sexual or psychological abuse or punishment."). The facility must also ensure that necessary steps are taken to protect residents from abuse and neglect. See id. at § 483.430(d)(1) ("The facility must provide sufficient direct care staff to manage and supervise clients. . . ."). Finally, a critical component in keeping residents safe is an effective incident management system, i.e., a system for reporting and investigating incidents involving serious injuries to residents, tracking and trending these incidents, and implementing and monitoring corrective action to avoid future incidents. See id. § 420(d)(2)-(4) (facility must "ensure that all allegations of mistreatment, abuse and neglect, as well as injuries of unknown source, are reported immediately . . .").

Woodbridge's own documents reveal that residents suffer frequent injuries: approximately 1,597 incidents were recorded in the 12 months from April 2002 until March 2003. These incidents included approximately 433 accidents, 533 self-inflicted injuries, 135 peer-inflicted injuries, 48 incidents of neglect, and 53 incidents of undetermined origin. The majority of Woodbridge residents are non-ambulatory, and therefore, are restricted in their ability to move without assistance from staff. Nonetheless, many residents suffered serious injuries including fractures to arms, knees, fingers, fibula (smaller bone between knee and ankle), toes, tibia (larger bone between knee

and ankle), femur (thigh), clavicle, as well as broken ribs, open head wounds, human-inflicted bites, broken teeth, a severed fingertip, facial contusions, and welts caused by physical objects. As described in more detail below, Woodbridge's failure to protect residents from harm stems from inadequate supervision, the failure to prevent staff abuse and neglect, and an inadequate incident management system.

1. Inadequate Supervision

We found that residents suffered many serious injuries because Woodbridge fails to supervise the residents adequately, see id. § 483.430(d)(1), and fails to provide adequate information to direct-care staff regarding crucial behavioral problems. The death of Philip George[2] in December 2002 illustrates these deficiencies. On December 26, 2002, Mr. George entered the kitchen through a door which staff had failed to lock, and began to stuff bread in his mouth. He choked on the bread and was pronounced dead upon arrival at the hospital. Although staff were supposed to maintain "eye contact" every 15 minutes, and investigation notes indicated that staff were actually present during the incident, no one could explain the cause of the incident. A similar lack of supervision was reflected in an incident approximately four months before his death, in which Mr. George lost a fingertip after it was severed by a closing window. We also discovered that staff had not been trained regarding his tendency to put choking hazards into his mouth, despite the abundant documentation of this tendency throughout his thirty-seven years at Woodbridge.

Even in instances where known behavioral risks were communicated to direct-care staff, we found that staff repeatedly failed to address these behavioral issues adequately, neglecting to provide adequate supervision. We set forth a number of illustrative examples below:

- Rose Kimbers sustained welts and abrasions to her left calf, thigh, buttock, and shoulder as a result of being hit with a broom by a peer on December 16, 2002. The facility's investigation discovered that the aggressor had a history of using objects such as brooms to attack other residents, and staff had been instructed to keep such items out of her reach. Woodbridge determined that this instruction had not

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[2] In order to protect the residents' privacy, we use pseudonyms throughout the letter. We will provide a list of actual names to the State under separate cover.

been conveyed to all of the current staff, resulting in the December 16 attack. In addition, although the aggressor's history of aggressive behavior required specialized, direct eye contact supervision, the December 16 incident indicates that staff did not provide such supervision.

- Fred Benton was taken to the hospital for dehydration and weight loss on December 2, 2002. A CAT scan revealed ingestion of multiple foreign bodies throughout his small and large intestines. Mr. Benton has a history of "pica," or ingesting inedible objects, such as bibs, soaps, toys, and clothing. Facility investigators determined that staff were aware that he needed close supervision, yet staff did not provide sufficient supervision to keep him from ingesting objects. Nor did any staff member see him ingest even one of the multiple objects.

- Lily Feldman was attacked on October 16, 2002 by Barbara Pullin, who bit her repeatedly on the face, neck, and arms, resulting in 15 sutures. The physician reported that Ms. Feldman's numerous injuries took several minutes to inflict. Ms. Pullin, the aggressor, has a known history of biting others that was amply documented in her records. Nonetheless, staff did not intervene when they observed Ms. Pullin entering Ms. Feldman's bedroom, as they were occupied in checking on another bedroom "which appeared to be in turmoil." Investigation notes concluded that "[i]nsufficient staff minimums on the 11:15 P.M. - 7:15 A.M. shift also appear to have played a role in this incident."

Facility records also reveal that residents routinely suffer injuries of unknown origin, further indicating Woodbridge's failure to supervise residents and keep them safe. Many instances of harm occurred when staff were not present. Generally accepted professional practice recognizes that serious injuries of unknown origins constitute potential evidence of abuse or neglect, incompetent or insufficient supervision, a failure to intervene when indicated, or ineffective monitoring systems. Federal regulations require that responsible direct care staff be present throughout the day to take prompt, appropriate action in response to incidents. See id. § 483.430(c)(2). See also id. § 483.420(d)(1) ("facility must provide sufficient direct-care staff to manage and supervise clients in accordance with their individual program plans"); id. § 483.430(e)(1) ("facility must provide each employee with initial and continuing training that enables the employee to

perform his or her duties effectively, efficiently, and competently."). Below are representative examples of injuries of unknown origin:

- Valerie Ruiz suffered a fracture to her left femur on July 1, 2002. Woodbridge determined that the injury was not self-inflicted, yet staff could not provide any explanation as to how or when the injury had occurred. Investigators determined that the fracture could not have been caused by her own actions.

- Steven Hadad, who is blind, was discovered on June 11, 2002 with lacerations on his nose and chin, requiring sutures. Although staff were supposed to be supervising Mr. Hadad on a one-on-one basis, at all times, no one could explain his injuries.

- Daniel Schwartz was diagnosed on April 28, 2003 with a fractured left foot after staff noticed discoloration. The cause and approximate date of the fracture were unknown.

- On February 23, 2003, staff discovered that Becca Mayfield had a sprained ankle. The next day, on February 24, 2003, after noticing that Ms. Mayfield's hand was swollen and bruised, staff also discovered that she had an acute fracture of the fifth finger of the left hand. Staff were unable to identify a cause for either of the injuries.

- Patrick Burke was found on December 18, 2002 with a swelling on his right buttock. X-rays taken at the hospital revealed a fracture to his fibula (area between the knee and ankle). The cause and the timing of the fracture were unknown.

During our investigation, we learned that in an apparent effort to discover unwitnessed injuries in a timely manner, two staff members perform complete body checks at the change of every shift. In some cases, this procedure involves stripping the residents virtually naked and inspecting the resident's entire body. As reflected in the injuries described above, however, this practice does not detect all injuries in the timely manner as intended. Pursuant to generally accepted professional standards, this practice should not serve as a substitute for adequate supervision. In addition to being ineffective, this highly intrusive practice violates residents' privacy rights. Residents' privacy rights should not be sacrificed due to staff's inability to supervise adequately. See id. § 483.420(a)(7)

(facility must "provide residents with the opportunity for personal privacy and ensure privacy during treatment and care or personal needs").

2. Abuse and Neglect

In violation of federal law, staff abuse and neglect of Woodbridge residents are ongoing. Youngberg, 457 U.S. at 324 (residents have the right to safe conditions). See, e.g., 42 C.F.R. § 483.420(a)(5) (facility must ensure that residents are not subjected to physical, verbal, sexual or psychological abuse or punishment). Our review of facility incident reports and investigations confirmed that residents are being subjected to a pattern of staff abuse and neglect. The following incidents are representative examples of abuse and neglect that occurred to Woodbridge residents within the six months before our tour:

- In August 2002, Bill Weathers was diagnosed with a fractured arm. After obtaining X-rays from the hospital, Woodbridge determined that the fracture was caused by a twisting motion of the arm with substantial force. Facility investigators concluded that the staff member conducting one-on-one supervision of Mr. Weathers actually committed the abuse. On February 19, 2003, less than six months later, a second one-on-one staff person abused Mr. Weathers. According to the investigation report, the staff member grabbed Mr. Weathers by the neck, applied pressure, and shook him back and forth. The staff worker then grabbed Mr. Weathers by the collar, lifted him from his wheelchair, and pushed him back into the wheelchair several times. The facility failed to track the earlier incident of abuse, thereby failing to identify risks and prevent further incidents.

- On July 31, 2002, Marina Todd was discovered with multiple red marks on her neck, upper back, right flank, right upper arm, left thigh, and left leg. Facility investigators determined that staff had hit Ms. Todd with Ms. Todd's purse strap and buckle. In another incident, on October 9, 2002, investigators found that Ms. Todd was hit on the back of her head by staff who then picked up Ms. Todd's purse and threw it at her.

Particularly disturbing is that confirmed abusers are sometimes reassigned to client care. Generally accepted professional standards provide that when reinstating such employees, facilities must take measures (i.e., by assigning a

staff member to an area where there is no contact with residents) to protect residents. Being able to return to former duties, following substantiated findings of abuse or neglect, not only places residents at risk, but also promotes a culture where it is perceived that abuse and neglect are tolerated. Although State officials have informed us that such staff are retrained and closely supervised when reassigned to another living unit, we are concerned about the adequacy of these corrective measures, given the significant deficiencies we have identified in supervision, training, and monitoring.

3. Inadequate Incident Management

Federal regulations and generally accepted professional standards of care require that facilities track and trend incident data to identify potentially problematic trends, and to identify, implement, and monitor implementation of corrective action. See id. § 483.420(d)(2)-(4) (requiring that incidents be investigated and appropriate action taken). An essential component of an adequate incident management system is the act of reporting incidents. Although Woodbridge's data tracking system does a good job of tracking and analyzing what is centrally reported, Woodbridge fails to ensure that incidents are consistently centrally reported. Woodbridge's failure to report and track a significant number of incidents and injuries constitutes a substantial departure from professional standards, compromising Woodbridge's ability to protect residents adequately.

For example, upon reviewing a variety of Woodbridge records, including active treatment notes, cottage occurrence logbooks, client group books, and behavior records, we discovered that injuries noted in residents' individual files did not have corresponding incident reports, and therefore, were not included in the central data management system that tracks the total number of incidents and injuries. In fact, staff confirmed, according to their understanding of procedure, that incident reports often are not filled out for client-to-client aggression and self-injurious behavior. This systemic failure to report self-inflicted and client-to-client incidents and injuries further leads to the false impression, expressed by some facility staff, that the frequency of incidents or injuries has been decreasing.

The primary cause of Woodbridge's under-reporting of incidents is its failure to develop a consistent reporting system. Contrary to generally accepted standards of professional practice, Woodbridge has not developed and implemented a

consistent set of policies and procedures for what constitutes injuries and how they should be reported. See id. § 483.420(d)(1) ("The facility must develop and implement written policies and procedures that prohibit mistreatment, neglect or abuse of the client.").

Below are representative examples of incidents involving repeated self-injurious behavior and assaults that were not centrally reported or tracked. We discovered these incidents when reviewing cottage logs or treatment notes:

- In August 2002, Teresa Ng injured herself 113 separate times. Not a single one of these injuries was formally reported in the central reporting system. Some incidents included her grabbing the flesh of her hands and arms with her teeth and banging her head on her bedrails.

- Frank Pitosi hit other residents on May 13, 2002, June 13, 2002, May 15, 2003, and June 15, 2003. However, the team meeting in September 2002, reviewing Mr. Pitosi's psychotropic medication treatment plan, mistakenly noted that since his aggressive behavior was stable (i.e., no aggressive incidents in the months of May and June 2002), his psychotropic medication would not be adjusted. If the 2002 incidents of aggression had been centrally reported, then the team might have been able to avoid subsequent outbursts in May and June of 2003 by adjusting Mr. Pitosi's medication accordingly.

- Marina Petrone grabbed, scratched or hit other residents on November 7, 2002, November 15, 2002, December 3, 2002, December 24, 2002, and December 26, 2002. Only one of these incidents was actually reported on an incident report form and placed into her file.

Patterns of aggression by residents like Ms. Petrone are impossible to detect in the absence of accurate reporting. Woodbridge's efforts to protect other residents from aggressive residents, as well as to help those aggressive residents learn not to respond aggressively, are therefore substantially hindered by under-reporting.

B. BEHAVIOR PROGRAMS, RESTRAINTS, AND HABILITATION

Woodbridge's residents are entitled to reasonable safety, freedom from unreasonable restraint, and habilitative treatment adequate to ensure safety and facilitate the ability to function free from restraints. Youngberg, 457 U.S. at 324; Clark,

794 F.2d at 87; Scott v. Plante, 691 F.2d 634, 638 (3rd Cir. 1982). Woodbridge fails to provide adequate psychological services to meet the individualized needs of the residents with behavior problems. Specifically, Woodbridge: (1) provides residents with ineffective behavioral programs; (2) exposes residents to undue restraint; and (3) provides inadequate habilitation treatment and activity programs.

Generally accepted professional practice recognizes that psychological interventions, such as behavior programs and/or habilitation plans, are used to address individuals' behavior problems. However, many Woodbridge residents who require behavioral treatment are simply not provided such treatment. As described below in more detail, these deficiencies reinforce residents' problem behaviors, exposing residents to a significantly increased risk for injury and abuse, and compromising residents' opportunities for placement in the most integrated setting.

1. Behavior Programs

Woodbridge's behavior programs are ineffective and substantially depart from generally accepted professional standards. Generally accepted professional standards of practice provide that behavior programs should be: (1) based on adequate functional assessments; (2) implemented as written; and (3) monitored and evaluated adequately. Ineffective behavior programs increase the likelihood that residents engage in maladaptive behaviors, therefore subjecting them to unnecessarily restrictive interventions and treatments.

Positively, psychologist caseloads are manageable at Woodbridge, with some psychologists appropriately having smaller caseloads in units where there is a higher concentration of residents with problem behaviors. In addition, there are para-professionals who assist the psychologists with ongoing duties and responsibilities in meeting residents' needs. However, these commendable aspects of Woodbridge's behavior programs are ultimately unavailing in the face of the program's significant deficiencies.

a. Functional Assessments

It is generally accepted professional practice that there be an adequate and current functional analysis in all cases prior to the initiation of psychological treatment. A functional assessment is a professional assessment technique that identifies the particular positive or negative reinforcement variables

prompting or maintaining a challenging behavior for a given individual. See 42 C.F.R. § 483.440(c)(3) (describing the various factors an assessment must include). By obtaining a greater understanding of the causes of challenging behaviors, professionals can attempt to reduce or eliminate these causal factors, and thus reduce or eliminate the challenging behaviors. Without such informed understanding of the cause of behaviors, attempted treatments are arbitrary and ineffective.

However, in all but one of the 24 cases we reviewed, we found no evidence that the functional assessment had been revised or updated based on a lack of progress in existing behavioral objectives, as reflected in repeated incidents and injuries. We found currently used functional analyses that were dated 1999, 1996, 1993, and in one startling case discussed in greater detail below, 1991. In each case, the functional analysis was not updated to match the more current information in the resident's behavior file.

A particularly disturbing yet representative case involves Chris Smith, who is on a highly restrictive behavior management program to prevent occurrences of hand-mouthing.[3] For an average of seven hours per day, he wears a custom-made helmet with turtleneck, padded domed lids, lock, and transparent face shield. The functional analysis that serves as documentation for his current helmet program was completed on June 5, 1991. Upon reviewing his chart, we discovered that on July 25, 2002, Woodbridge's Behavior Management Committee determined that the helmet was being used excessively, and that Mr. Smith becomes agitated when the helmet is used and repeatedly tears at his helmet. We also found that his chart indicated little or no progress in decreasing his hand-mouthing behavior or skin breakdown. Yet, by the time of our investigation in June 2003, there had been no updated functional analysis, and Mr. Smith was continuing to wear the helmet.

b. Behavior Program Implementation

Consistent and correct implementation of adequate and appropriate behavior programs is required if progress is to be made on the behavior program. However, as stated above, the

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[3] Hand-mouthing is self-stimulatory behavior whereby a person causes his or her hands or fingers to come in contact with his or her lips, tongue or inside of the mouth. Continuous hand-mouthing behavior can result in skin breakdown from blisters and infection.

written programs themselves are deficient. The attempted implementation of these inadequate programs only magnifies these inadequacies, resulting in a level of care that substantially departs from generally accepted professional standards of care. Poor implementation of programming places Woodbridge residents with behavior problems at risk of continued harm, continued exposure to restrictive intervention procedures, and continued unnecessary institutionalization.

Staff at Woodbridge fail routinely to implement properly the formal written behavior programs for the residents. Our on-site observations and interviews with staff across all shifts and units who were responsible for implementing the written behavior programs revealed that few, if any, knew how to implement the programs properly and effectively. Staff we interviewed revealed significant errors in their recall of basic and essential elements of the behavior programs. Facility records also reveal that this is a widespread problem. For example, we reviewed charts containing clear evidence that on repeated instances, the programs were not implemented consistently as written. As a result of inadequate implementation, we found reports of adverse events, such as injuries, fractures, aggression, self-injurious behavior, abuse, and neglect.

The problems with implementing the behavior programs are largely caused by Woodbridge's failure to train staff adequately. See id. § 483.430 (e)(2) ("For employees who work with clients, training must focus on skills and competencies directed toward clients' . . . needs."). See also id. § 483.430(e)(3) ("Staff must be able to demonstrate the skills and techniques necessary to administer interventions to manage the inappropriate behavior of clients."). The staff we interviewed revealed that they received some classroom training and were asked to read each program, but virtually all admitted that they were not asked to demonstrate their competency or understanding of how to implement the programs. Interviews with the Woodbridge psychologists confirmed that they did not provide the staff with competency-based training, such as training that results in effectively prompting residents and reinforcing and shaping appropriate behavior.

As a result of this inadequate implementation of behavior plans, residents continue to face a substantial risk of harm. For instance, as previously detailed, in December 2002, Woodbridge resident Mr. George stuffed his mouth with bread and choked to death. During his 37 years as a resident at Woodbridge, he had developed a history of severe pica behavior and was recognized as having a potential of risk for choking.

Nevertheless, staff who were supervising him that night had not received proper in-service training on his behavior program for pica. Without this training, staff failed to implement his behavior program appropriately, resulting directly in his death.

c. Monitoring and Evaluation

Generally accepted professional standards of care require that facilities monitor residents on behavior programs in order to evaluate a resident's progress and to make decisions regarding future treatment. Without the necessary monitoring and evaluation, residents are in danger of being subjected to ineffective, inadequate, and/or unnecessarily restrictive treatment, as well as avoidable injuries related to untreated behaviors.

Woodbridge's monitoring efforts are inadequate in that they fail to utilize a systemic quality assurance improvement process for reviewing trends with regard to the development, implementation, and effectiveness of behavioral services and the resulting outcomes for residents. There is no ongoing facility-wide tracking of critical aspects of providing psychological services at Woodbridge, such as the use of restraints, the use of emergency procedures, the development and update of functional analyses, and staff implementation of programs. In addition, not one of the behavior programs we reviewed specified the procedure used to monitor or supervise staff implementation of the behavior programs.

We found that, as a likely result of inadequate monitoring, Woodbridge had made few, if any, changes in the behavior programs in the decade prior to our review. This is evident even though many of these residents suffered significant events that would normally prompt a revision or an update. Consequently, we found multiple cases that revealed no significant progress in reducing the rate of problem behaviors. Indeed, some of the behaviors actually increased with the passage of time, suggesting that Woodbridge's procedures for treating problem behaviors have not been effective. Residents with continuing problem behaviors suffered additional harm when, in the face of unsuccessful behavior programs, they were then subjected to means of control such as chemical restraint and the use of emergency mechanical restraints, <u>see</u> <u>infra</u> Section II.B.2. In addition, the facility's failure to monitor and evaluate adequately residents' problem behaviors has made it more difficult for many of these residents to transition to more integrated community settings.

2. Restraints

The right to be free from undue bodily restraint is the "core of the liberty protected by the Due Process Clause from arbitrary governmental action." Youngberg, 457 U.S. at 316 (citing Greenholtz, 442 U.S. at 18). See also Clark, 794 F.2d at 87 (recognizing that there are to be appropriate limits on the use of restraints on residents in institutions consistent with Youngberg); 42 C.F.R. § 483.13(a) (a resident "has the right to be free from any physical or chemical restraints . . . not required to treat the resident's medical symptoms").

Woodbridge is trying to decrease restraints and limit their use. We understand that a number of steps have been initiated to reduce the unnecessary use of restraints in some cases. Commendably, the facility reported a notable drop in the use of emergency mechanical restraints immediately prior to our tour. Nonetheless, Woodbridge still uses undue restraint to control certain residents with behavior problems. As previously discussed, the lack of adequate behavioral practices results in untreated behavior problems that, in turn, lead to an unreasonable reliance on restrictive intervention measures, including physical restraints and medication.

Overall, Woodbridge uses unreasonable restraints that pose a significant risk of injury to Woodbridge residents. Consistent with generally accepted professional practices, highly restrictive interventions are to be included in a behavior program only when justified by the results of an adequate formal functional analysis and only when there is evidence that less restrictive procedures have been ineffective or are unsafe. Generally accepted professional standards of practice require that restrictive interventions: (1) will be used only when residents pose an imminent danger to themselves or others or in limited emergency situations; (2) will be used only after a hierarchy of less restrictive measures has been attempted; (3) will be continued only when proven effective; (4) will not be used as punishment, for the convenience of staff, or in the absence of or as an alternative to treatment; and (5) will be terminated as soon as the resident no longer presents a danger to himself or herself or others. See also 42 C.F.R. § 483.450(b)(3) ("Techniques to manage inappropriate client behavior must never be used for disciplinary purposes, for the convenience of staff or as a substitute for an active treatment program.").

We found that non-medical restraints,[4] including helmets and four-point restraints, were used without support by data from a formal functional analysis or by data from a previous treatment trial with a less restrictive intervention. In many of these cases, restraints were implemented on an unplanned, emergency basis rather than as part of the residents' written behavior programs. Several residents were placed in restraints for nearly all of their waking hours, regardless of whether they had exhibited the problem behavior. Some residents even slept in restraints at night, when they were not a danger to themselves or others. Several times over the course of four days, we also observed instances where residents were not released from restraints for a "break" pursuant to facility policy and generally accepted professional practices.

A few residents had been subjected to more than 100 applications of restraint per month for several months in the year preceding our tour. For example, Sally Weld was restrained 370 times in one month; Chris Smith was restrained 238 times in a month; and Peter Gottlieb was restrained 105 times in a month. In March 2003, Paul Ryan was in restraints 151 times for over 700 hours; Jim Sosa was in restraints 124 times for almost 700 hours; and Saul Burd was in restraints 190 times for over 650 hours. In the first quarter of 2003 alone, Woodbridge reported overall that there were 46 uses of emergency mechanical restraint, 709 uses of mechanical restraint when a resident exhibited a challenging behavior, and 465 uses of mechanical restraint whether or not a resident exhibited a challenging behavior. These figures strongly suggest that lesser restrictive measures either were not utilized at all or were not given an adequate trial prior to resorting to more restrictive interventions.

We found that programs we reviewed provided for the use of highly restrictive interventions, such as two-point or four-point mechanical restraints, jumpsuits, or restrictive helmets with face masks. The facility labeled some of these restraints, however, as "medical" restraints. While these restraints were legitimately put in place initially for the resident's protection based on a medical reason, their use continued beyond the

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[4] Medical restraints are restraints put in place initially by physicians, following individual evaluation, for the resident's protection based on a medical reason, e.g., seizures, preventing removal of sutures, recent surgery, gait problems. Such restraints are ordered for a limited time, pending resolution of the medical event. In contrast, non-medical restraints generally have no such medical basis.

initially prescribed period for non-medical purposes, i.e., behavior control purposes. This practice suggests that these restraints are being used as a substitute for, rather than as a part of, a programmatic behavior intervention, keeping ineffective plans in place.

Consequently, staff's excessive and continued use of mechanical restraints reflects that the facility has failed to develop appropriate ways to treat residents' problem behaviors, and that staff utilize restraints either for their own convenience, or to control behaviors in lieu of effective behavioral treatment. Psychology staff informed us that they were aware of this significant problem regarding the excessive use of mechanical restraints, including highly restrictive measures.

Staff also engage in the dangerous practice of prone personal restraint, which involves non-mechanical restrictions by staff such as tight physical holds and lying on top of residents who are usually on the floor, face down. The use of prone restraints on persons with developmental disabilities poses a significant risk of injury to the resident, including death by asphyxiation, caused by excessive weight on the resident's back and compression of the chest.

In addition to physical restraints, many residents are also being subjected to chemical restraints in that they receive psychotropic medication without the benefit of a concomitant and less intrusive behavior program. We found that 31% of Woodbridge's residents receive psychoactive medications for the treatment of a behavioral or psychiatric disorder. However, only nine percent of Woodbridge's residents receive behavioral treatment program services. This practice indicates that many residents with significant behavioral disorders are only being medicated for their problems and that minimally acceptable behavioral treatment and related psychological services are not being provided.

Regulations require that persons given drugs to control inappropriate behaviors receive concomitant behavioral services - which are less intrusive - along with the medication prescribed by psychiatry. See, e.g., id. § 483.450(e)(2) ("Drugs used for control of inappropriate behavior must be . . . used only as an integral part of the client's individual program plan that is directed specifically towards the reduction of and eventual elimination of the behaviors for which the drugs are employed.");

see also id. § 483.420(a)(6) ("Ensure that clients are free from unnecessary drugs and physical restraints and are provided active treatment to reduce dependency on drugs. . . ."). Because Woodbridge's behavior programming is critically inadequate, the use of chemical restraints is often unreasonable, exposing residents to unnecessary risk of harm from side effects. We discuss the harm of inappropriate medication and side effects in more detail below.

3. Habilitation Treatment and Activity Programming

Woodbridge residents are entitled to adequate habilitative treatment to ensure safety and facilitate the ability to function freely from restraints. See Youngberg, 457 U.S. at 324; see also Clark, 794 F.2d at 95 (Becker, J., concurring) (following Youngberg, and noting that "for the state to allow disabled persons' skills to deteriorate is as sure a denial of their liberty as is their confinement to an institution"). Woodbridge's habilitation treatment services and activity programming are inadequate in that services are seriously limited, staff have not been trained adequately to implement the habilitation plans, and residents do not receive habilitation services in appropriately integrated settings.

An effective habilitation treatment program provides residents with regular activities designed to assist them develop new skills and practice skills previously learned. See 42 C.F.R. § 483.420(a)(6) (facilities participating in Medicaid must "[e]nsure that clients are free from unnecessary drugs and physical restraints and are provided active treatment to reduce dependency on drugs and physical restraints"). However, many Woodbridge residents receive little meaningful training. During our visit, we observed a low level of staff interaction with the residents. Too often, residents were not engaged and the staff did not attempt to engage them. On several occasions during our tour, we saw numerous residents sitting idly in chairs - even though staff were present. When residents are not provided with adequate habilitation treatment programming, not only are they less likely to learn adaptive behaviors, but they also are more likely to seek attention through maladaptive behaviors, such as aggression and self-injury. Since a lack of meaningful activity often exacerbates behavior problems, the result often is an increase in the use of restraints.

The lack of adequate activity programming is due, in part, to inadequate staff training. Generally accepted professional standards of care require structured, ongoing performance-based (i.e., competency-based) training for staff who implement

activity programming. See also id. § 483.430 (e)(1) ("The facility must provide each employee with initial and continuing training that enables the employee to perform his or her duties effectively, efficiently, and competently.").

Even for those residents whose habilitation plans provided for meaningful activities, Woodbridge fails to provide staff with competency-based training on how to implement habilitation plans. The implementation of the individualized habilitation plans we reviewed was inconsistent and often did not follow the written habilitation plans. For example, we observed a resident rocking on her seat as she sat unattended. Her behavior then progressed to hitting her head and pulling her hair more aggressively as time passed. According to her plan, this was her way of communicating discomfort and staff were to determine if she needed to stand up or go to the bathroom. Staff, however, seemed unaware that her behavior warranted a response.

Generally accepted professional practice also recognizes that residents with developmental disabilities should receive services, such as day programming and vocational training, in integrated settings wherever possible so that they may acquire new skills, grow and develop, and enhance their independence. This aspect of habilitation is integral in developing residents' independence skills and making them better candidates for community placement. See also id. § 483.440(a)(1) ("Each client must receive a continuous active treatment program, which includes . . . related services . . . directed toward . . . [t]he acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible."). Indeed, Woodbridge staff acknowledged that residents benefit whenever they are able to leave their living cottages for programming. Staff informed us that they have seen first-hand how Woodbridge residents with behavior problems rarely exhibit these behaviors while they are engaged in day programming, and that many residents could benefit from such programming. Woodbridge, however, fails to provide residents with adequate day program and vocational opportunities.

At the time of our visit, no Woodbridge resident traveled off-campus to work at a job. Therefore, for all residents, vocational activities are limited to the institutional setting. In addition, most of the Woodbridge residents receive minimal, if any, day programming, and the day programming they receive is entirely within their residential building on-campus. Woodbridge's two workshop programs handle only a small number of residents, though they have the potential to serve many more. Only about 60 residents receive day programming at one workshop.

Still fewer residents participate in the more specialized programs offered at the other workshop, which opened in March 2002. This workshop offers a garden program, an art program, a boutique, a bilingual program, and a computer program. However, the bilingual program serves fewer than ten residents and the art program serves only about a dozen residents, each for just one hour per week. The art program serves only eight residents for three hours per week. In sum, Woodbridge fails to provide its residents with adequate day programming and vocational opportunities.

C. MEDICAL CARE

Woodbridge fails to provide residents with adequate medical care, including psychiatric services, neurological care, nutritional and physical management, and therapy services. See Youngberg, 457 U.S. at 315, 323, 324 (residents have a constitutional right to adequate medical care). See also Scott 691 F.2d at 636 (providing that Youngberg establishes right to adequate treatment). To its credit, Woodbridge has retained the consultative services of a highly qualified and nationally recognized psychiatrist. In addition, Woodbridge employs neurologist consultants for residents who require a specialized level of medical care.

Despite these isolated positive practices of care, our investigation revealed that particular aspects of psychiatric services and neurological care are significantly deficient, therefore exposing residents to substantial risk of harm. We also found problems with nutritional and physical management and therapy services.

1. Psychiatric Services

The provision of psychiatric care at Woodbridge is flawed and substantially departs from generally accepted professional standards of practice, as well as violates federal regulations. See Youngberg, 457 U.S. at 324 & 323 n.30 (facilities must provide residents with adequate medical care and "decisions normally should be made by persons . . . with appropriate training in areas such as . . . physical therapy, or the care and training of the retarded."); Scott, 691 F.2d at 636 (providing that Youngberg establishes the right to adequate treatment); Halderman v. Pennhurst State Sch. & Hosp., 784 F. Supp. 215, 217 (E.D. Pa. 1992) (approving comprehensive consent decree which settled outstanding deficiencies, including drug use that was "extraordinarily high" and the use of psychotropic drugs for control and not for treatment of institutionalized persons with

developmental disabilities). See also 42 C.F.R. § 483.420(a)(6) (clients must be free from unnecessary drugs). Specifically, Woodbridge fails to: (1) provide residents with adequate assessments and/or psychiatric diagnoses, as well as re-evaluations of diagnoses when necessary; (2) provide residents with adequate and timely access or follow-up to psychiatric services, even when directly requested by the psychiatric consultant; and (3) monitor adequately the side effects of psychotropic medications.

a. Psychiatric Assessments and Diagnoses

Generally accepted professional standards of care require that initial psychiatric diagnoses be based upon a complete psychiatric assessment. Once an initial diagnosis is made, ongoing assessments should be conducted to ensure that a timely re-evaluation of the resident's condition and behavior is made and treatment is adjusted accordingly.

Adequate assessments are critical in diagnosing mental illnesses in persons with developmental disabilities because these individuals often cannot effectively describe their own conditions. Consequently, a psychiatrist should make diagnoses based on a full assessment of an individual's symptoms, and then prescribe interventions to assess if the diagnoses were appropriate according to professionally accepted diagnostic criteria. For example, if a psychiatrist hypothesizes that a resident's self-injurious behavior is the result of depression, then he or she might institute a trial of an anti-depressant medication. If the resident responds to this intervention, then the assumption that the resident was suffering from depression is strengthened. For this reason, the ongoing process of evaluating a diagnosis and treatment according to an individual's response is critically important.

Woodbridge's psychiatric assessments and diagnoses, however, are highly deficient. We found a multitude of examples where medical charts failed to include initially assigned diagnoses, substantially departing from generally accepted professional standards of care. We found some charts with potential diagnoses recorded informally in the record. Without clearly indicated and documented diagnoses, there is no legitimate basis for psychiatric treatment. Furthermore, an informally recorded diagnosis poses a significant risk of harm, as treatment might depart from the intended diagnosis.

For example, Gary Platt received Mellaril, an anti-psychotropic medication used for the treatment of behaviors such as schizophrenia or other acute psychotic episodes, but had no diagnoses listed in his medical chart. Another resident, John Peters, a 27-year-old resident with profound mental retardation, was evaluated by the psychiatrist for aggression. His treatment began in 1995 and continued through May 2003. Psychiatric notes indicated that this resident was receiving medication used to treat a mood disorder, although there was no mood disorder diagnosis in his medical records. In fact, his chart failed to contain any psychiatric disorder diagnosis. In both of these instances, the lack of any formal diagnosis casts doubt on the adequacy of the residents' treatment, raising a question whether they should have been receiving medications for psychiatric disorders at all.

Woodbridge also fails to provide ongoing assessment or diagnosis of those residents who have been assigned diagnoses. Without ongoing re-evaluations of the presumptive diagnoses, the result is likely to lead to treatment not corresponding to the initial assigned diagnoses. None of the charts we reviewed reflected any documentation of ongoing re-evaluation of the diagnoses. Again, this failure places the residents at risk for inappropriate diagnoses, resulting in inappropriate treatment of psychiatric disorders. The hazards of such inadequate treatment include inappropriate medication, exposure to unnecessary side effects of medication, and injury resulting from untreated behaviors.

b. Inadequate and Untimely Access to Psychiatric Services

The manner in which Woodbridge provides access to psychiatric care is highly inadequate. Generally accepted professional standards of care require initial evaluation and ongoing follow-up by a qualified psychiatrist. We found numerous examples where Woodbridge failed to provide residents with the treatment they needed, even when the psychiatric consultant specifically requested the need for follow-up care. Woodbridge's practices clearly depart from these standards by seriously delaying access to psychiatric care, and by failing to provide essential feedback to the psychiatric consultant.

As of June 2003, Woodbridge's records reflected that approximately one-third of all residents were receiving psychotropic medications. Woodbridge utilizes a contractual

psychiatric consultative service on a referral basis to meet the needs of the residents. The psychiatrist provides his consultation services only three days per month and sees approximately only six to ten residents each visit. The significant delays in access to psychiatric services may be attributable, in part, to this inadequate staffing configuration. The facility's consultant psychiatrist informed us that he has insufficient time to provide the necessary evaluations and follow-up that are needed by Woodbridge residents with mental illness.

In addition, residents with significant psychiatric symptoms and problematic behaviors rarely receive a prompt follow-up psychiatric consultation after an initial consultation. Many Woodbridge residents therefore continue to receive highly restrictive interventions and psychotropic medications without a psychiatrist's oversight, input, or consultation. This practice is in direct contravention to generally accepted professional standards of care. The Woodbridge psychiatric consultant acknowledged that he often fails to see residents when he should, such as shortly after they have been placed in mechanical restraints or given emergency doses of psychotropic medication. Consequently, we found that it was not uncommon for months to pass after an initial evaluation before a resident received the necessary follow-up assessment.

These deficits are compounded by additional deficient practices. First, the psychiatrist does not schedule consultations. Instead, a non-mental health staff member establishes the list of residents who are to be seen during the psychiatrist's visit. This non-mental health professional frequently "bumps" residents from the list for residents designated by their cottage physicians as needing emergency psychiatric care. Furthermore, Woodbridge fails to provide the psychiatrist with any organized feedback for him to ascertain whether individuals have been inappropriately bumped from his schedule or whether those residents designated as "emergency" are indeed emergency cases.[5]

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[5] We learned, for example, that one cottage physician sent to the staff member who assembles the names, a list of all residents taking psychotropic medications as emergency cases to be seen by the consultant. Woodbridge later determined that only one of the residents on the list actually constituted an emergency. Although it is unclear whether the cottage physician compiled this list to secure timely care for those residents, the absence of a reliable system for prioritizing actual emergencies

Second, the psychiatrist does not have ongoing direct interaction with the residents' cottage physicians or treatment teams. Many psychotropic medication regimens used in the treatment of mood or anxiety disorders involve the use of multiple medications with serious side effects. Therefore, generally accepted professional standards of care provide that close supervision by a psychiatrist is often needed. Woodbridge substantially departs from these generally accepted professional standards of care, placing residents at risk for inadequate treatment of psychiatric disorders and related behavioral and medical problems.

The following are a few examples of Woodbridge's failure to provide adequate and timely access to psychiatric care:

- Carlton Depuis is a 50-year-old resident who suffers from profound mental retardation and is essentially non-verbal. His initial mental health evaluation took place on January 16, 1996 and his noted behaviors over a one-year period included increasing social withdrawal, significant weight loss, increased sleep problems, and increased head slapping. He was placed on an anti-depressant medication, and at his next psychiatric consultation, which did not occur until nearly two years later, his dosage was increased with a note from the psychiatric consultant that Mr. Depuis's condition be reviewed in "2 months." Nonetheless, Mr. Depuis was not seen again by a psychiatrist until four years and five months later. During this prolonged period, Mr. Depuis was subjected to medication even though many subsequent notes in his chart indicated that Mr. Depuis had been stable for more than a year. Generally accepted professional practice requires attempts at medication reduction following documentation that a resident's condition has stabilized. By delaying follow-up treatment or evaluation, Woodbridge substantially departs from this professional practice.

- Colette Merchant is a 41-year-old resident with profound mental retardation and a history of assaultive and self-injurious behavior. She has been diagnosed with bipolar disorder, obsessive compulsive disorder, and pervasive developmental disorder. She also receives a complex regimen of three psychotropic medications but continues to be assaultive and self-injurious. Despite this resident's assaultive history and complex medication regimen, she was

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while ensuring that all residents receive timely care is still problematic.

seen by a psychiatrist only six times in the nearly five-year period between September 1998 and June 2003. The consequences of her behavior included being restrained, as well as placed in seclusion, approximately five times between March and May 2003. Each incident represented a missed opportunity for Woodbridge to intervene with psychiatric or behavioral services in an attempt to reduce this resident's behavioral problems.

c. Inadequate Monitoring of Medications

Generally accepted professional standards and federal regulations require that facilities provide regular and systematic review of psychotropic medications to ensure the continued effectiveness of the prescribed regimen. See id. §§ 483.450(e)(3), (4) (drugs used to control inappropriate behavior must not be used until justified, and drugs must be monitored closely). This practice is a critical component of psychiatric care. Many psychotropic medications carry serious side effects, resulting in physically debilitating conditions, and therefore, residents must be carefully monitored.

Woodbridge, however, fails to monitor, measure, and document the side effects of psychotropic medication accurately and consistently. We were unable to find any documentation of monitoring of side effects for many residents. Many of Woodbridge's residents receive combinations of psychotropic drugs and most of these drugs have known side effects. Failure to assess side effects properly poses numerous serious risks, including the exacerbation or creation of additional medical and/or behavioral problems.

The facility's failure to obtain laboratory results for monitoring side effects of medication in a timely manner further exacerbates the potential for harm. Laboratory tests ordered by the psychiatrist or attending physician are necessary to monitor residents adequately for drug side effects to avoid potential harm. We found many examples where the psychiatrist ordered blood tests, but the tests were either never taken or the results were not returned to the facility. In one example, we discovered that a resident's blood sample was ordered to be assessed for drug toxicity, but the laboratory results were lost because her blood tube had leaked. We found no evidence of a replacement test. In addition, for this same resident, Woodbridge failed to obtain electrocardiograms (used to monitor for cardiac drug side effects) that were ordered by the psychiatrist, thereby delaying appropriate psychiatric treatment and exposing the resident to a

risk of heart damage. The medical director admitted that Woodbridge does not have a monitoring system in place to address these problems to avoid potentially harmful medical results.

2. Neurological Care

Woodbridge fails to provide adequate care and monitoring for residents with seizure disorders. At the time of our tour, 300 (approximately 60%) of the residents at Woodbridge were taking anti-seizure medication. Generally accepted professional standards of care provide that individuals with a confirmed neurological disorder who are receiving anti-convulsant medications should be monitored regularly by a neurologist for appropriateness of treatment and medication.

However, due to insufficient availability of neurological services, only a small number of residents with seizure disorders who are receiving anti-convulsant medications actually receive such neurological services. Through two neurologist consultants, Woodbridge provides only three to five hours total of on-site consultation per month, and fewer than two hours per month of consultation limited to reading EEGs. As with psychiatric consultations, Woodbridge fails to assure that neurology consults are even initiated as requested by medical health professionals or that follow-up neurology visits occur at the recommended interval.

In addition, Woodbridge fails to monitor adequately the use of anti-convulsant medications. These failures place residents at a significant risk of harm such as uncontrolled and/or increasingly frequent seizures, and unnecessary exposure to potentially harmful drugs with dangerous side effects. Side effects of these drugs include: significant impairment in motor performance; decline in cognition; and increased risk for pathological fractures.

The following examples illustrate our findings:

- Nick Pelozzo has a difficult-to-control seizure disorder with numerous episodes, some of which have resulted in injuries. Despite the significant fact that Mr. Pelozzo was hospitalized from May 30 until June 2, 2002 following an episode of status epilepticus,[6] he was not seen by a

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[6] Status epilepticus is a prolonged sustained seizure rendering the individual unconscious, possibly resulting in brain damage.

neurologist until September 12, 2002, approximately three months later. According to generally accepted professional standards, such an episode should have triggered an immediate neurological consultation.

- Felicity Kaufmann, a 42-year-old resident with profound mental retardation and a seizure disorder, was seen by the neurologist on January 10, 2002. The neurologist recommended an increase in medication and a follow-up evaluation in three months. Despite suffering increasingly frequent seizures, Ms. Kaufman was not seen again until March 25, 2003, over one year later.

- Luis DeRosa is a 38-year-old resident diagnosed with profound mental retardation and a seizure disorder. On November 4, 2002, his attending physician recommended a neurological consultation and increase in anti-convulsant medication. On November 28, 2002, Mr. DeRosa suffered recurrent seizures, necessitating an emergency administration of Valium and admission to the hospital for four days. No changes were made to his regularly prescribed medication, despite his ongoing seizures. He was not provided with the requested neurology consultation until March 14, 2003, over four months later.

3. Nutritional and Physical Management

Woodbridge substantially departs from generally accepted professional standards in the nutritional and physical management services it provides to the residents. Specifically, Woodbridge fails to assess adequately residents' complex and interrelated nutritional, physical, and medical needs in the areas of positioning, alignment, mobility, nutrition, and medical care. In addition, Woodbridge provides inadequate seating systems, alternate positioning options, transfer services, and mealtime supports. These deficiencies place the residents at an increased risk for losing functional skills and developing health problems such as chronic respiratory infection, aspiration, esophagitis (inflamed esophagus), gastroesophageal reflux disease ("GERD"), poor skin integrity, and musculoskeletal deformity.

In the six months preceding our visit, dozens of Woodbridge residents were hospitalized, and some residents even died, as a result of physical, nutritional, and medical concerns that were addressed inadequately. Many individuals who died exhibited health risk factors and may have benefitted from comprehensive assessments that they never received. Generally accepted

professional standards of care require that facilities like Woodbridge provide comprehensive assessments of an individual's specialized physical and nutritional needs. Upon reviewing medical records, we found that there was no system to identify risk factors to prompt such a formal assessment of residents' physical, nutritional, and medical concerns. For example:

- Gladys Fisher had contractures (permanent shortening of muscle, tendon, or scar tissue, producing deformity or distortion), scoliosis (a curvature of the spine), severe dysphagia (difficulty in swallowing), a history of anorexia and weight fluctuations, a history of chronic upper respiratory infections, and confirmed aspiration of fluids. Despite these complex issues, Woodbridge did not conduct a comprehensive assessment to address her physical and nutritional management concerns. These concerns progressively worsened before her death in December 2002.

- Scott Timber had a history of gastrointestinal bleeding, vomiting, extreme weight loss, pneumonia, aspiration, GERD, mild dysphagia, esophagitis, pica, and scoliosis. In December 2002, Mr. Timber was transferred for the fourteenth time in three years to the hospital due to frequent vomiting. His admitting diagnosis included gastrointestinal bleeding, sepsis, and renal insufficiency. Mr. Timber died in December 2002 as a result of cardiac arrest, respiratory failure, and pneumonia. Despite these recurring complex and interrelated issues, Woodbridge never conducted a comprehensive assessment in an attempt to alleviate his condition.

Woodbridge also fails to provide adequate or appropriate seating systems for residents who need them. Generally accepted professional standards require that residents be provided with safe and appropriate seating systems that allow for proper alignment and support. Proper support and alignment are critical in preventing serious health problems such as aspiration pneumonia, GERD, choking, and musculoskeletal deformity. Commendably, Woodbridge conducts twice-weekly wheelchair seating clinics by qualified professionals who evaluate the resident to make sure that the resident's wheelchair properly supports the resident. Unfortunately, the seating clinics are not producing wheelchair seating systems that meet residents' needs. At the time of our tour, there were approximately 290 residents in wheelchairs. We directly observed at least 90 residents in seating systems that did not provide adequate support and alignment. The following are representative examples of inadequate seating systems:

- We observed Susan Wilson in a completely inadequate system, albeit brand new. As a result, Ms. Wilson sat in her wheelchair with her shoulders twisted to the left and her head leaning very close to her lap tray, which resulted in significant compression of her abdomen. This positioning placed Ms. Wilson at great risk for reduced functional skill performance, problems with digestion and elimination, increased risk of aspiration and choking, and for the development of contractures and deformities.

- We observed Zach Furman in a wheelchair that did not adequately support and align his head and body. His trunk leaned severely to the left; his head was not supported; his pelvis was not aligned; and his abdomen was compressed. This position placed him at great risk for problems with digestion and elimination and increased risk of aspiration and choking. Proper alignment is critical for Mr. Furman in treating his GERD condition.

In addition, Woodbridge fails to utilize adequate alternate positioning options to prevent the development of pressure sores. The techniques and devices that Woodbridge uses only slightly reduce the point of contact that exists when the residents are in their wheelchairs, and therefore, do little to prevent the development of pressure sores. The techniques and devices that Woodbridge uses for alternate positioning further fail to provide residents with the support and alignment necessary for adequate ventilation and digestion, and the prevention of contractures or physical deformities. Thus, Woodbridge's failure to provide adequate positioning options exposes residents to significant harm and/or risk of harm. For example:

- We observed Ed Davis lying flat on his back without any support for his head, trunk, and extremities. This position resulted in continued weight on his back and buttocks even though the reason he was out of his wheelchair was to provide pressure relief to those areas. Mr. Davis has had two incidents in 2002 of pressure sores including a Stage II pressure sore[7] on his buttocks a month before our tour and another pressure sore on another portion of his buttock six

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[7] A Stage II pressure sore is characterized by a blister. At this stage, a partial layer of skin is injured and the wound is no longer superficial. If not identified and treated aggressively, a Stage II pressure sore may progress to a Stage III wound that extends through all of the layers of the skin and is a primary site for serious infection.

months earlier. Mr. Davis also has a documented history of chronic constipation, fecal impaction, vomiting, gastrointestinal bleeding, moderate to severe dysphagia, aspiration, unexplained weight loss, hip dislocation, and scoliosis. All of these conditions are linked to and exacerbated by poor positioning and inadequate alignment or support.

- Ten residents at Woodbridge who use wheelchairs developed pressure sores during the year prior to our visit. The lack of adequate alternate positioning either directly caused or exacerbated the development of pressure sores with these residents.

Since many of Woodbridge's residents are non-ambulatory, they rely upon staff to transfer them from one position or location to another. Generally accepted professional standards of care and regulations require that staff be adequately trained in and utilize safe and appropriate physical support in the course of transfers. Woodbridge's direct support staff, however, neither possess sufficient knowledge of nor utilize appropriate physical assistance and transferring techniques. As with problems with implementation of mealtime assistance strategies described below, we found that staff did not receive skill-based competency training regarding such techniques.

We observed numerous examples of improper assistance and transfer techniques that placed both the resident and staff at risk of serious injury. We directly observed unsafe handling techniques, such as dropping or sliding a person on a surface, and not using brakes during transfers. These unsafe techniques place residents being assisted at serious risk for fracture or other injury. In addition, our document review confirms that improper and inadequate assistance and transfer techniques have resulted serious injuries to Woodbridge residents. For example:

- Dorothy Goldstein, who is totally dependent upon staff and cannot move independently, suffered numerous injuries when a staff member, using improper handling techniques, dropped her on the ground during a bath in July 2002. These injuries included a facial contusion with black and blue discolorations to the right cheek and around the right eye, two small black and blue discolorations on the right arm, and two small black and blue discolorations to the right knee. Staff also failed to report the incident centrally.

- Karen Yoder suffered a fractured tibia on September 27, 2002, as a result of the direct-care staff using improper handling and transfer techniques.

- In September 2002, Victoria Klein sustained a fracture to her right foot. Investigators determined that the injury might have occurred by having her foot banged against a hard surface while being transferred by staff. Staff gave conflicting reports regarding whether transfers from Victoria Ruiz's wheelchair required one or two staff members, suggesting that staff were not aware of the proper transfer procedure.

Woodbridge also does not provide residents with adequate mealtime supports. Woodbridge's direct-support staff are not adequately trained in mealtime assistance techniques and do not implement these techniques correctly. We found that staff did not receive competency-based training regarding mealtime assistance strategies. Generally accepted professional standards of practice and regulations require that staff not only have an understanding of mealtime feeding techniques, but also can demonstrate the related skills to ensure safety through competency-based training. See id. § 483.430(e)(2) (requiring training to focus on skills and competencies). We observed numerous examples of staff presenting food and drink at too fast a pace and in quantities that were too large. In addition, we observed staff not following mealtime plans. These deficient practices place residents at great risk of choking or aspirating.

4. Therapy Services

Finally, Woodbridge fails to provide adequate and appropriate physical and occupational therapy services for the residents. A lack of adequate therapy services exposes residents to harm including an increased risk of respiratory, gastrointestinal, and skin integrity complications. According to Woodbridge professionals, Woodbridge utilizes a "nursing home model" of physical and occupational therapy in which the goal is merely for residents to maintain the status quo rather than for residents to acquire new skills and enhance abilities. This approach substantially departs from generally accepted professional practice.

Generally accepted practice requires a developmental center like Woodbridge to conduct a comprehensive evaluation to determine the residents' baseline ability to function in different environments, and then to develop meaningful goals for the resident with specific outcome measures. If the resident

meets the specific outcome measures, then new goals are set; if the resident fails to achieve the outcome measures, then the facility must reevaluate the supports and services and implement revised ones. Woodbridge does not engage in this process with the residents.

D. SERVING PERSONS IN THE MOST INTEGRATED SETTING APPROPRIATE TO THEIR INDIVIDUALIZED NEEDS

New Jersey is failing to serve Woodbridge residents in the most integrated setting appropriate to their individualized needs, in violation of Title II of the ADA and the regulations promulgated thereunder. One such regulation - the "integration regulation" - provides that "[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d). The preamble to the regulations defines "the most integrated setting" to mean a setting "that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." Id. § 35, App. A at 450. The ADA provides that: "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. In furtherance of the ADA, President George W. Bush issued the New Freedom Initiative, an executive order that identifies as a high priority for this Administration the removal of barriers to equality and the expansion of opportunities available to Americans living with disabilities. See Exec. Order No. 13217, §§ 1(a)-(c), 66 Fed. Reg. 33,155 (June 18, 2001).

In construing the anti-discrimination provision contained in Title II of the ADA, the Supreme Court established a three-prong test to determine when jurisdictions are required to provide community-based treatment for persons with mental disabilities. The Court held that jurisdictions are required to provide such services when: (1) "an individual 'meets the essential eligibility requirements'" for protections, supports and services in a community-based program, based upon reasonable assessments of the individual's treating professionals; (2) "the affected persons do not oppose such treatment"; and (3) the placement can be "reasonably accommodated," taking into account the resources available to the jurisdiction and the needs of others who are similarly situated. Olmstead, 527 U.S. at 602, 607.

As described in more detail below, the State is failing to meet its obligations by not providing Woodbridge residents with adequate assessments and adequate information so that they can make informed decisions about community placements. In addition, once Woodbridge determines that a resident is appropriate for community placement, residents are not moved into the community in a reasonable amount of time. Indeed, in June 2003, we discovered that only five out of the 100 residents on a waiting list recommended as qualified for community placement by Woodbridge's own professionals were scheduled to be placed into the community by the end of 2003. Thus, based on its own records, Woodbridge has failed to provide the most integrated setting appropriate to the individualized needs of at least 95 of its residents. However, given the significant deficiencies in Woodbridge's assessment process and Woodbridge's failure to inform residents adequately about community placement, the number of residents for whom community placement would be appropriate could well exceed Woodbridge's waiting list of 100 residents.

1. Inadequate Assessment

Woodbridge's interdisciplinary teams fail to conduct reasonable assessments to determine whether each resident could be served in a more integrated setting and to identify the services each resident would need in a community-based setting. During our visit, we discovered many instances where the interdisciplinary teams failed to make any recommendation regarding whether Woodbridge was the most integrated setting appropriate for the individual residents. We also observed interdisciplinary team meetings in which the team recommended retention of the residents in the institution simply because it did not know whether community-based staff could meet the medical and behavioral needs of the residents. A social worker argued against community placement, for example, citing a presumed absence of one-on-one staff support in the community. In the same meeting, other team members stated that they were unaware of the homes or services available in the community. A lack of familiarity regarding services in the community does not justify continued isolation in an institutional setting.

In assessing residents for community placement, treating professionals are required to form an independent judgment based on an assessment of whether the resident can be appropriately served in the community with proper supports. See Olmstead, 527 U.S. at 602. Despite this requirement, it appears that treating professionals recommend that residents remain at Woodbridge based upon the perceived lack of available community alternatives. In order for the State to meet its legal duty to

identify residents appropriate for placement into the community, Woodbridge's treating professionals must conduct adequate assessments of each resident, and understand community supports that can be implemented to support residents' medical, behavioral, and/or health care needs.

2. Inadequately Informed Choices Regarding Community Placement

Generally accepted professional standards mandate that, in order for individuals, and, as appropriate, their families or guardians, to make informed choices about community placement, staff must provide them with adequate information about community options, resources, and supports. A decision to stay in or leave an institution is not meaningful if it is not informed.[8] Woodbridge, however, does not assure that residents and their families or guardians are fully informed when deciding on community placement. We observed one interdisciplinary team meeting in which a resident's mother expressed an interest in placing her daughter into the community. The social worker, however, then reminded the mother of her past objections to community placement. The mother then expressed opposition to placement without any effort by the team to elicit the basis for the mother's resistance or to address the mother's concerns. In another meeting, the social worker stated that she "suspected" that the family would want the resident to remain at Woodbridge while admitting that no actual discussion had even taken place. The interdisciplinary team members accepted this response without having a broader discussion with the family about community-placement options.

3. Resources Available to the State

The State has invoked fiscal concerns to justify the inadequate number of community placements for Woodbridge residents. However, at the time of our visit in mid-2003, we were informed that Woodbridge had a sufficient budget to provide

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[8] Ensuring informed consent is an essential element in community placement. The federal Centers for Medicare and Medicaid Services ("CMS") sent a letter of guidance to states regarding the content of an effective discharge plan, including the need to promote an informed choice about community placement. Specifically, the letter stated that the plan should provide opportunities for informed choice to persons with disabilities and their representatives. See Letter from Centers for Medicare and Medicaid to State Medicaid Directors (Jan. 14, 2000).

for at least 20 transfers. Nonetheless, only five residents from the waiting list of 100 were actually scheduled to be transferred into the community by the end of the year. Indeed, data and information provided by Woodbridge show that the pace of community placements has been slow for years. In the eight and a half years between 1995 and June 2003, Woodbridge transferred out of the facility only 51 residents, or an average of six residents per year. Moreover, many of these transfers were not transfers to the community but instead to similarly restrictive settings, such as to other developmental centers and nursing homes.

Thus, fiscal constraints do not appear to account for the inadequate number of community placements. Rather, the continued institutionalization of individuals who should reside in a more integrated setting appears to rest largely upon the deficient discharge planning process described above, see supra Section II.D.2.

III. MINIMAL REMEDIAL MEASURES

To remedy the identified deficiencies and protect the constitutional and statutory rights of Woodbridge residents, New Jersey should implement, at a minimum, the following remedial measures:

A. Protection from Harm

1. Ensure that residents are supervised adequately by trained staff and kept reasonably safe and protected from harm and risk of harm.

2. Impose appropriate discipline and corrective measures with respect to employees involved in substantiated cases of abuse or neglect.

3. Develop and implement adequate policies and procedures regarding incident reporting and the conduct of investigations of serious incidents. Train staff and investigators fully on how to implement these policies and procedures. Centrally track and analyze trends of incidents and injuries so as to help prevent future occurring events. Include systemic recommendations in investigation reports to prevent future occurrence of injury.

B. Behavior Programs, Restraints, and Habilitation

1. Provide residents with the behavioral, psychological, and habilitation services needed to meet the residents' ongoing needs.

(a) Provide residents with behavior problems with an adequate functional assessment so as to determine the appropriate treatments and interventions for each person. Ensure that this assessment is interdisciplinary and incorporates medical and other unaddressed conditions that may contribute to a person's behavior.

(b) Develop and implement an adequate array of comprehensive individualized habilitation, training, and behavior programs for the residents. The programs must be developed by qualified professionals consistent with accepted professional standards and must be developed to reduce or eliminate risks to personal safety, unreasonable use of bodily restraints, prevent regression, and facilitate the growth, development, and independence of every Woodbridge resident.

(c) Train the appropriate staff how to implement the behavior and habilitation programs and ensure that they are implemented consistently and effectively. Record appropriate behavioral data and notes with regard to the person's progress on the programs.

(d) Monitor adequately the residents' progress on the programs and revise the programs when necessary to ensure that residents' behavioral and habilitation needs are being met. Provide ongoing training for staff whenever a revision is required.

2. Ensure that restraints are never used as punishment, in lieu of training programs, or for the convenience of staff.

(a) Implement a protocol that places the appropriate limits on the use of two and four-point restraints, as well as the routine use of emergency chemical and unplanned physical or mechanical restraints.

(b) Ensure that only the least restrictive restraint techniques necessary are utilized, and, except in an emergency, that restraints are used only in connection with a behavioral treatment program.

(c) Provide quality assurance programs to ensure that restraints are used effectively and properly. Ensure that ineffective behavior programs are modified or replaced in a timely manner.

(d) Document and track fully the use of personal control and seek to reduce its use significantly.

(e) Ensure that all residents receiving psychotropic medications for behavior control receive effective psychological services, including assessment, diagnosis, and medication management, on a timely and on-going basis.

3. Provide residents with habilitation, training, and behavioral programs that are adequate to protect residents' personal safety and prevent unreasonable use of restrictive interventions.

C. **Medical Care**

1. **Psychiatric Services**

(a) Provide adequate psychiatric services consistent with accepted professional standards to residents who need such services.

(b) Ensure that each resident with mental illness is provided with a comprehensive psychiatric assessment diagnosis, treatment, and follow-up care. Provide new assessments and/or revisions to any aspect of the treatment regimen when appropriate. Develop and implement mental health services in close collaboration with the facility's psychologists so as to provide coordinated behavioral care.

(c) Provide adequate psychiatry hours to meet the needs of the residents.

(d) Assure that psychotropic medication is only used in accordance with accepted professional standards and is not used in lieu of a training program, for behavior control, in lieu of a psychiatric or neuropsychiatric diagnosis, or for the convenience of staff. Ensure that no resident receives psychotropic medication without an accompanying behavior program or documentation justifying no program. Provide competency-based training to staff regarding residents' behavioral programs.

(e) Improve the quality of behavioral and other data provided to psychiatrists to better ensure adequate psychiatric treatment for each person.

2. **Neurological Care**

(a) Provide adequate neurological care in accordance with generally accepted professional standards.

(b) Provide adequate and appropriate routine, chronic, and emergency seizure management to all residents with a seizure disorder at Woodbridge in accordance with generally accepted professional standards of care.

(c) Develop a method of tracking and evaluating the appropriateness of neurological care of residents.

3. **Nutritional and Physical Management, and Therapy Services**

(a) Ensure that residents receive adequate nutritional and physical management services in accordance with generally accepted professional standards as follows:

(1) Provide comprehensive assessments to each resident with physical and nutritional support needs.

(2) Develop and implement appropriate support strategies.

(3) Monitor regularly the progress of the residents with physical and nutritional support strategies and revise the strategies where necessary.

(b) Ensure that residents receive adequate and appropriate seating systems and alternative positioning options, as follows:

(1) Provide comprehensive assessments to each resident with a need of a seating system and alternative positioning.

(2) Ensure that residents are properly positioned in safe and appropriate seating and alternative positioning devices.

(3) Monitor regularly residents who utilize seating systems and alternative positioning options to ensure that they are meeting the residents' needs.

(c) Provide competency-based training to all staff who are responsible for resident transfers, positioning, and alignment. Develop and implement a system to monitor all resident transfers, positioning, and alignment and conduct additional competency-based training where needed.

(d) Provide competency-based training to all staff who are responsible for providing mealtime assistance to residents. Ensure that, during mealtime, residents are properly aligned and positioned and that staff are presenting food and fluids at an appropriate pace and in an appropriate manner. Develop and implement a monitoring system to ensure safe and effective implementation of mealtime assistance and plans.

(e) Provide each resident with adequate and appropriate physical and occupational therapy services in accordance with accepted standards of care.

D. **Serving Persons in the Most Integrated Setting**

1. Provide services to individuals with developmental disabilities in the most integrated setting appropriate to their needs. The State shall:

(a) Develop a comprehensive community placement plan to provide community residences and other services to meet the individual needs of the residents already identified as eligible for community placement and establish a schedule to place such individuals in community-based programs.

(b) Conduct and update reasonable interdisciplinary assessments of each resident to determine whether the resident is in the most integrated setting appropriate to his/her needs. Obtain adequate information regarding community-based options for placements, programs, and improvement.

(c) If it is determined that a more integrated setting would appropriately meet the individual's needs and the individual does not oppose community placement, promptly develop and implement a transition plan that specifies actions necessary to ensure safe, successful transition from the facility to a more integrated setting, the names and positions of those responsible for these actions, and corresponding time frames.

(d) Ensure that residents and their families and/or guardians are fully informed about community placement opportunities and services.

(e) Monitor community-based programs to ensure program adequacy and the full implementation of each individual's habilitation plan.

* * *

We hope to be able to continue working with the State in an amicable and cooperative fashion to resolve our outstanding concerns with regard to Woodbridge. Provided that our cooperative relationship continues, we will forward our expert consultants' reports under separate cover. Although their reports are their work - and do not necessarily reflect the official conclusions of the Department of Justice - their observations, analyses, and recommendations provide further elaboration of the issues discussed in this letter and offer practical assistance in addressing them.

In the unexpected event that we are unable to reach a resolution regarding our concerns, the Attorney General is empowered to institute a lawsuit pursuant to CRIPA to correct deficiencies of the kind identified in this letter, 49 days after appropriate officials have been notified of them. 42 U.S.C. § 1997b(a)(1).

We would prefer, however, to resolve this matter by working cooperatively with you. We have every confidence that we will be able to do so in this case. The lawyers assigned to this matter will be contacting your attorneys to discuss this matter in further detail. If you have any questions regarding this letter, please call Shanetta Y. Cutlar, Chief of the Civil Rights Division's Special Litigation Section, at (202) 514-0195.

Sincerely,

R. Alexander Acosta
Assistant Attorney General

cc: The Honorable Peter C. Harvey
Attorney General
State of New Jersey

James Davy
Commissioner
Department of Human Services
State of New Jersey

John Dougherty
Chief Executive Officer
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