April 8, 2003

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

Re: New Lisbon Developmental Center, New Lisbon, New Jersey

Dear Governor McGreevey:

On March 20, 2002, we notified you that we were initiating an investigation of conditions at the New Lisbon Developmental Center (hereinafter "New Lisbon"), pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. New Lisbon is the largest state-operated facility serving persons with developmental disabilities in New Jersey. In May and June 2002, we conducted two separate visits to New Lisbon with expert consultants in various disciplines. At an exit interview conducted on the last day of each facility visit, we verbally conveyed our preliminary findings to counsel and to senior officials from the facility and the State Department of Human Services. Consistent with the requirements of CRIPA, we are now writing to apprise you of our findings.

I. INTRODUCTION

During our investigation, we evaluated whether residents of New Lisbon have been afforded their constitutional and statutory rights. Residents of state-operated facilities have a right to live in reasonable safety and to receive adequate health care, along with habilitation to ensure their safety and freedom from unreasonable restraint, prevent regression and facilitate their ability to exercise their liberty interests. Youngberg v. Romeo, 457 U.S. 307 (1982). Similar protections are accorded by federal statute. See, e.g., Title XIX of the Social Security Act, 42 U.S.C. § 1396; 42 C.F.R. Part 483, Subpart I (Medicaid Program Provisions). The State is also obliged to provide services in the most integrated setting appropriate to individual resident's needs. Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132 et seq.; 28 C.F.R. § 35.130(d); see also Olmstead v. L.C., 527 U.S. 581 (1999).

At the time of our visits in May and June 2002, the census at New Lisbon was approximately 600 residents who range in age from 18 to 87 years old. The residents' diagnoses range from mild to profound mental retardation. The residents possess diverse abilities and functional levels. Some residents require more staffing supports to meet their daily needs, while others are much more independent and capable of meeting their own needs. Many of the residents have swallowing disorders, seizure disorders, ambulation issues, or other health care needs. A significant portion of the New Lisbon population is medically complex and requires assistance at mealtimes and other frequent monitoring. There are a number of persons at the facility who have developed maladaptive behaviors. More than 375 New Lisbon residents have been diagnosed as having one or more psychiatric disorders.

We conducted our investigation by reviewing medical and other records related to the care and treatment of persons who live at New Lisbon; interviewing administrators, professional and direct care staff, and residents; and conducting on-site surveys of conditions and practices.

Based on our review, we have concluded that there are numerous conditions and practices that violate the constitutional and statutory rights of New Lisbon residents. The facts that support our findings of unlawful and unconstitutional conditions at New Lisbon are set forth below along with the minimal actions that we believe are necessary to remedy these conditions. During our site visits, State and facility officials acknowledged that New Lisbon was a "work in progress" and that it was just beginning to undertake major reform initiatives. Positive developments include that New Lisbon has expanded its workforce by about 40 percent over the past year, creating more than 250 new direct care positions and seven additional psychologist positions. New Lisbon has also created an Incident Response Unit to conduct certain investigations. Nonetheless, it is clear that these reform initiatives have just begun. We also note that the facility is staffed predominately by dedicated individuals who are genuinely concerned for the well-being of the persons in their care. Further, we wish to acknowledge and express our appreciation for the extensive cooperation and assistance provided to us by the administrators and staff of the facility, as well as senior officials from the State Department of Human Services, especially James W. Smith, Jr., the Director for the Division of Developmental Disabilities within the Department. Mr. Smith made several trips from Trenton to meet with us, explain the State's system and answer our questions. We hope to continue to work with the State of New

Jersey and officials at New Lisbon in the same cooperative manner in addressing the problems that we found.

II. PROTECTION FROM HARM

New Lisbon fails to protect its residents from harm or risk of harm. The facility's incident reports and data management documents reveal a high number of incidents which resulted in an injury to a resident. For example, in the ten months prior to our arrival - from early June 2001 to early April 2002 - there were approximately 4,400 recorded incidents at New Lisbon involving mostly minor, but also moderate and major injuries to residents.[1] From January 2001 to May 2002, there were over 500 incidents classified as moderate or major, including resident-on-resident assaults, abuse or neglect, and deaths. Of the 500 moderate or major incidents, 242 resulted in fractures, or lacerations requiring sutures, staples or dermabond to close the wounds. In addition, in the five months preceding our first tour, it appears that incidents and injuries were increasing. New Lisbon documents reveal the following:

- A May 2002 risk analysis by the facility concluded that at New Lisbon the "quantity of injuries has continued to increase since January 2002. The number of injuries of unknown origin has almost doubled since this period."

- A March 2002 analysis of injury data concludes that the rate of minor injuries caused intentionally by other people had increased to levels not seen since September 2001.

- That same injury analysis concluded that from the beginning of 2002 until March 2, 2002, self-inflicted injuries increased from 25 injuries per week to over 40 injuries per week.

---

1 The facility categorizes incidents as either minor, moderate, or major incidents. Minor incidents that result in injuries generally include minor bites, bruises, superficial abrasions, blisters and minor cuts. Moderate and major incidents that result in injuries are more severe and include fractures and lacerations that require sutures, staples, or dermabond. Regardless of severity, these injuries can result from a variety of sources including staff abuse or neglect, resident aggression and altercations, resident self-injurious behavior ("SIB"), seizures, falls, or other unknown causes.

The increase in the number of incidents and injuries at New Lisbon in 2002 may be due to recent efforts at the facility – a very positive development – to better record incidents that might have gone unrecorded before. It may also be due to the additional staff presence at the facility who may now observe incidents that might have been unobserved before. However, it may be that, indeed, conditions and practices at the facility are deteriorating and New Lisbon is less safe now than it has been in the past. In the weeks preceding our tours, there had been numerous significant injuries to residents:

- Paul,[2] 4/5/02, needed four staples and three sutures to close a head wound after an altercation with a peer.

- Andy, 4/2/02, injured the side of his head due to self-injurious behavior ("SIB"), requiring five sutures.

- John, 3/26/02, suffered a laceration on his forehead underneath his helmet from an unknown source, requiring three staples.

- Edward, 3/26/02, suffered a right eye laceration from SIB, requiring five sutures.

- Anthony, 3/25/02, fell out of his wheelchair, and suffered abrasions on his finger, ear, head, a bruise on his back, and a fractured thumb; a few days later, on 4/3/02, it was also determined that he had a fractured right clavicle.

- James, 3/17/02, needed five staples to close his head laceration due to an altercation with a peer.

- Richard, 3/13/02, was struck by a peer and needed seven staples to close the laceration on his head; his fifth finger was also fractured.

- Matthew, 2/9/02, a resident who is required to have constant supervision, was found by staff with a large shoe-shaped bruise on his chest.

- Jeffrey, 2/3/02, was found in his cottage grimacing in pain

---

2 In order to protect the identity of residents, we use pseudonyms throughout the letter.

and refusing to move, and a few days later, on 2/8/02, 21 staples were placed in his hip, which had been fractured after being pushed by a peer.

Recently, New Lisbon has begun to keep track of residents who are most often victims of intentional injury by others; it also keeps data on the aggressor. This is important so that the facility may take prompt, effective action to ensure that a resident victim is protected from harm in the future. Nonetheless, there are other systemic concerns with regard to how the facility manages incidents. For example, existing policies fail to include critical definitions for abuse and neglect. The facility also does not train staff on certain critical aspects of incident reporting and does not provide sufficient training on how to promote residents' safety. While improved recently, the facility does not adequately analyze incident and injury trends. The facility does not conduct adequate systematic analyses to predict when, where, and in whose presence important incidents occur, so that steps can be taken to reduce or prevent additional incidents. New Lisbon must do more to provide adequate supervision, staff training, and properly developed and implemented behavior programs given that most of the incidents referenced above were preventable.

Substantiated allegations of staff physical and verbal abuse against residents, as well as neglect, are ongoing. Below are a few examples, occurring in the weeks before our tours, demonstrating the facility's systemic failure to protect its residents from harm:

- Robert, 4/17/02 - staff member punched resident in the chest.

- Jennifer, 3/1/02 - staff member called resident degrading and undignified names.

- Adam, 2/27/02 - staff member forcefully pushed Alfred into his room, causing him to collide with a chair on the other side of the room.

- Henry, 2/27/02 - staff member took Henry and other residents to her house to clean up dog waste in her backyard.

- Angela, 2/24/02 - staff member was seen holding Angela's faceguard and shaking her head up and down while yelling at her.

- Wilson, 2/9/02 - staff member intentionally smeared glue on Wilson's face, and failed to remove the glue before it dried; removal of the dry glue was "painful."

- Paula, 1/25/02 - staff member slapped Paula in the face, and pinched her "because she is a 'dark-skinned black person' and bruises don't show up on her"; there were "2 large bruises on right breast"; staff member also struck "the heal of her hand on Paula's forehead"; staff member directed profanity at the resident and verbally threatened her.

- From January 1, 2002 through the time of our tour in early May 2002, over a half-dozen New Lisbon staff were caught sleeping while on duty.

It appears that New Lisbon is conducting timely investigations of serious incidents such as these and that staff accused of resident abuse are not allowed contact with residents until the investigation is completed. These are positive practices. Nonetheless, we uncovered several problems with the investigations at the facility. For example, the facility often delegates investigation authority to subordinates who may not be trained and/or qualified to conduct an investigation. Training provided to staff conducting investigations is inadequate both in terms of comprehensiveness and scope. In addition, the New Lisbon investigation reports often fail to include systemic recommendations to prevent further recurrence of injury. In June 2002, the facility, itself, found that 25 percent of the time, investigation reports "did not apply the findings of the investigation to prevent the event from happening again." A review of the unusual incident reports from March 2002 revealed that 50 percent of initial closed reports did not include actions taken to protect the victim from further incidents and that 78 percent failed to make recommendations to prevent the type of incident from happening again. Without adequate investigations and a system to address problems uncovered in investigations, residents will continue to be exposed to preventable incidents of harm in the future.

Another area of concern relates to corrective personnel action in cases where an allegation against New Lisbon staff is substantiated. The documentation provided to us reveals that the initial recommended discipline in substantiated cases is virtually always more severe than that actually meted out. For example, in the first few months of 2002, in the cases involving substantiated

allegations against staff and/or staff sleeping on duty, the facility recommended "removal" in nine cases. However, in none of those cases was termination actually accomplished. Instead, a typical penalty imposed was a ten-day suspension. Reduced penalties may promote a culture where it is perceived that abuse and neglect are tolerated.

III. PSYCHOLOGY AND BEHAVIORAL SERVICES AND PSYCHIATRY

New Lisbon fails to provide adequate and appropriate psychological services to meet the individualized needs of its residents with behavior problems. This deficiency is a contributing factor to a significant number of the incidents and injuries discussed above, which often stem from residents' inadequately addressed problem behaviors such as SIB, aggression, and "pica" (i.e., ingesting inedible objects).

In the year preceding our visit, New Lisbon took steps to address these problems. For instance, New Lisbon increased the number of psychologists at the facility by adding seven additional clinicians. Each living unit now has one full-time psychologist and one full-time behavior management technician. New Lisbon also contracted with the Liberty Health Care organization to write new behavior programs for all New Lisbon residents who need a behavior program. As of June 2002, New Lisbon reported that about 350 residents had a behavior program, many of which had been rewritten by Liberty.

It appears that the facility has recognized that its contract with Liberty did not solve the deficiencies in providing behavioral services to its residents. Part of the problem likely stems from the fact that Liberty provided no follow-up with regard to the implementation and monitoring of the programs. Moreover, the facility appears to have recognized that the newly-developed behavior programs were substandard and needed revision. For example, in February 2002, the facility's psychology committee minutes expressed "repeated concerns" about the quality of the behavior programs developed by Liberty. The minutes reveal that many programs already had undergone needed revision. There was an expressed concern that the behavior programs were based on functional analyses "that were not accurate ... or [were] dysfunctional or inappropriate."

A. Behavior Program Development

Despite the recent increase in psychology staff, the facility's current behavior programs do not contain all of the required

components and do not comport with generally accepted practice. For example, most New Lisbon behavior programs do not provide a detailed definition of each behavior in observable terms. Without a specific definition, there is likely to be inconsistency in implementation of intervention procedures and recording of data. In addition, the functional analysis process fails to adequately incorporate the direct observations of the treating psychologist, who should observe the resident in different settings and situations. Incorporating this element will benefit the residents because New Lisbon will be able to develop more effective interventions. New Lisbon behavior programs also do not adequately use positive reinforcement, even though systematic, individualized use of positive reinforcement is generally accepted as an effective way to reduce problem behaviors. Even where positive reinforcement is included, it is not specific enough to result in meaningful and consistent implementation. In addition, the teaching components of the behavior programs are not specific and do not provide staff with enough information to teach the alternative skill correctly and consistently.

Many of New Lisbon's problems with completing an adequate behavioral assessment, developing an effective behavior program, and monitoring its effectiveness, relate to the facility's failure to collect consistent and meaningful behavioral and other data. Without better data, it is hard to define initially the nature and scope of residents' behavior problems as well as measure residents' progress while treated with a behavior program. Direct care staff typically record data only at the end of the shift. This practice makes errors likely given that staff must record data for multiple residents over a prolonged period of time. It also hampers the collection of data that is individualized enough to identify triggering events, which would help provide needed treatment to residents. Finally, New Lisbon fails to check the reliability of the data collected and fails to check staff's implementation of data-recording.

Psychology staff at New Lisbon also are failing to include in behavior programs information about health conditions that may impact the occurrence of problem behaviors. Virtually all of the behavior programs reviewed made no mention of health-related issues. New Lisbon's behavioral programs often fail to consider precipitating resident health issues that may trigger behavior problems. In addition, New Lisbon may be treating certain problem behaviors with behavior plans or psychiatric interventions when they could be solved by addressing the underlying health concern.

B. Behavior Program Implementation

Consistent and correct implementation of behavior programs is required if progress is to be made on the behavior program. While each New Lisbon behavior program contains a section on how to respond to behaviors when they occur, most of the stated interventions are vague. This typically leads to inconsistent implementation. The programs often refer to facility-approved procedures without defining what they are and under what conditions they should be implemented. In addition, while each program contains specific skills to be taught to the residents, staff do not implement adequately the teaching components of the behavior programs. Implementation is often limited to recording unstructured activities rather than teaching from the structured behavior program.

The staff who implement the programs receive inadequate training and instruction. The result is that programs are often implemented in inconsistent and ineffective ways. Some staff reported having no contact at all with the psychologist and other staff claimed that they did not receive meaningful training on how to implement the behavior programs. In March 2002, internal documents acknowledged that New Lisbon direct care staff need more training in how to address residents' needs.

During our on-site tour, some New Lisbon staff could describe correctly how to respond to problem behaviors, but many other staff members' descriptions of how to respond to behaviors did not correspond to the behavior program. This can lead to a lack of progress or even an escalation in resident outbursts, possibly resulting in injury or restraints. Many staff members implemented their own interventions regardless of what was written in the programs. Staff sometimes described and implemented interventions that would actually reinforce problem behaviors. For instance, staff sometimes gave residents candy or soda after the residents were exhibiting problem behaviors. Inconsistent use of reinforcement can lead to undesirable outcomes. Positive reinforcement is applied inconsistently at New Lisbon largely because the behavior programs provide little direction or poor guidance with regard to how to address problem behaviors. We found other instances where staff addressed a problem behavior using a restrictive practice that was not fully explained in the behavior program.

In addition to poor implementation, New Lisbon fails to conduct adequate reviews and properly monitor residents' progress on their behavior programs. This problem is exacerbated by the facility's poor data collection process, as discussed earlier.

C. Restraints

New Lisbon residents have a right to be free from unreasonable use of restraints. New Lisbon reports that between January 1, 2001 and April 15, 2002, there were over 1,000 instances in which the facility restrained a resident using four-point wrist and ankle restraints.[3] In anticipation of our visit and in an effort to reduce the use of four-point restraints, the Risk Management Committee ordered staff to remove all four-point restraint equipment from all cottages, except Dogwood and Fern, no later than April 15, 2002. Based on this new directive, New Lisbon reports a significant reduction in the use of four-point restraints, from a high of over 200 applications in June 2001 to fewer than 50 applications in February 2002. For many residents, the almost daily use of four-point restraints has stopped. Nonetheless, the use of four-point restraints continues to be a problem as the facility still unnecessarily uses four-point restraints on certain residents. For example, between April 1, 2002 and June 14, 2002, in spite of the new facility directive to reduce the use of four-point restraints, New Lisbon subjected 19 residents to four-point restraints on 32 separate occasions.[4] The facility estimates that it still uses four-point restraints about six to eight times per week. New Lisbon aggregate data reveals that the average length of time in restraints is roughly the same now as it was a year earlier.

In June 2002, New Lisbon characterized its restraint usage as "continuing to remain low and may be trending downward ... the rate of mechanical restraint in the last three months is lower than any other time since this data has been recorded." However, substitute restrictions, i.e., psychotropic drugs, may have emerged to take the place of the four and five-point mechanical restraints. Or the

---

3 New Lisbon's documents also indicate that the facility sometimes applies a chest belt to residents who are in four-point restraints, making it a five-point restraint.

4 The information New Lisbon reported to us may under-report the use of restraint at the facility. For example, we found problems with regard to restraint data collection for Bradley. Data produced by New Lisbon revealed that Bradley had been involved in 98 documented incidents of restraint including helmet usage and four-point restraints between January 1, 2001 and April 4, 2002. However, in comparing that information with information contained on the living unit, we found an additional 39 incidents of restraints that were not included in the data produced by the facility.

mechanical restrictions may have taken on a different name, now labeled as "medical" devices. For example, in June 2002, the facility acknowledged:

> the use of Stat and short-term orders for medication to control behavior seems to be increasing. It is not clear if this type of restraint is truly increasing or if there had previously been under reporting ... Medical needs to ensure that these orders are communicated to the psychiatrist to aid in the evaluation of the effectiveness of regularly prescribed psychotropic medication ... Another red flag noted seems to be an increase in the use of medical safeguarding as the numbers of [emergency mechanical restraint] continues to decline. There has been a noted increase in the use of mitts in response to maladaptive behavior that is being recorded as medical safeguarding.

Indeed, New Lisbon reports that 30 residents have been subjected to "emergency/stat" behavior modifying medications between January 1, 2001 and April 15, 2002. A May 2002 facility document refers to using a PRN (or "as needed") injection of Ativan whenever resident Peter's "SIB cannot be controlled." The use of medication to control a person's behaviors on a PRN basis does not comport with generally accepted practice as it leaves too much discretion to non-physicians and is likely to lead to overuse of the medication which should be controlled and closely monitored by a physician.

New Lisbon also engages in the restrictive practice of "personal control" of residents, which involves manual contact by staff to restrict the residents' freedom of movement either partially or totally. Facility policy requires that staff review the use of personal control and record its use in a database. However, it was evident that it is not being recorded properly (if at all) and it is not tracked anywhere in the facility's databases. Thus, personal control does not appear in the facility's restraint reports or in the list of behavior programs that have restrictive components. There is no data on the use of personal control and little monitoring, training, and examination of how to reduce its usage. As a result, it is impossible to determine how often this restrictive practice is being used at New Lisbon. However, we know from house managers that the practice is being used. We also are troubled that this form of restraint may be hidden within the behavior programs that call for the use of "facility approved procedures."

A number of New Lisbon residents wear large, brown, padded helmets that appear heavy, uncomfortable, stigmatizing, and unduly restrictive. New Lisbon does not properly assess and monitor use of these helmet restraints to ensure that they are used as infrequently as possible (such as for protection from seizures or injuries related to gait problems) and that they are tailored to the person. The facility appears to be coming to an understanding that these helmets do not meet the residents' needs. For example, in April 2002, the New Lisbon Human Rights Committee concluded that a helmet of this type "is very intrusive and restrictive."[5]

New Lisbon demonstrated that reduction in the use of helmets can be accomplished safely. For example, in anticipation of our summer visit, the facility discontinued the use of these helmets for some residents, sometimes mere days prior to our arrival. At the time of our visit, all of these residents seemed to be doing well. New Lisbon produced for us a list of 35 individuals who still wear the helmets. New Lisbon reports that 12 residents were on fading plans and that about two dozen still need the helmets "as prescribed." Only eight had a behavior program; 27 residents did not have a behavior program, ostensibly needing the helmets for "medical" purposes. For those without a behavior program, the imposition of these helmets did not have to pass through the protections of the Behavior Management Committee ("BMC"), the Human Rights Committee and/or psychology review.

We also found that many residents would benefit from enhanced supervision and monitoring, thus reducing use of these helmets, especially when needed for "medical" purposes. In fact, our medical consultant characterizes the helmets used at New Lisbon as "ponderous, sensory-limiting headgear," and added that such helmets are not commonly used for medical reasons, even for persons with

---

5 The committee discussed the continued use of restrictive helmets in the context of one resident who demonstrates SIB. The committee concluded that he stops hitting himself on the head when the helmet is removed and certain objects are placed in his hands; he will also stop hitting himself when he engages in fingerplay and when he chews on an item; and that the helmet is not removed even when he stops slapping himself. The committee concluded that: "This means that [he] will remain in the helmet even when he does not pose a danger to himself. This is excessively restrictive and also seems to reduce the opportunities for him to learn that if he stops slapping, the helmet is not used."

severe seizures that cause sudden falls.

The facility's BMC is supposed to review at least quarterly all behavior programs with restrictions. However, the BMC failed to meet at all from late August 2001 through April 2002, a gap of about seven months. At that time, the committee's name was changed to the "Behavior Support Committee." The BSC appears to now be taking a more active review role, recommending that use of restraints for behaviors be reduced and discontinued for many residents, and that the reduction include a positive reinforcement component.

D. Psychiatric Services

New Lisbon provides inadequate and inappropriate psychiatric care and services to its residents with mental illness. As of April 1, 2002, New Lisbon reports that there were a total of 377 residents with mental illness who received psychotropic medications. Comparing this number with the number of residents on a behavior program (350), it appears that some New Lisbon residents may be receiving psychotropic medication without the benefit of an accompanying behavior program. This does not comport with generally accepted practice. Fortunately, the psychologists appear to be very involved in the psychiatric consultation process as they attend almost every psychiatry consultation meeting. This enhances interdisciplinary collaboration between the psychologists and the psychiatrists which should benefit the New Lisbon residents.

At the time of our visit, the facility was trying to meet the residents' mental health needs by contracting with part-time psychiatrists. However, New Lisbon appears to recognize that additional psychiatry hours are needed in order to meet the residents' needs. As a result, the facility is seeking to employ a full-time on-site psychiatrist and possibly two more in the near future. It appears that New Lisbon has also recognized recently that it needs to re-evaluate the psychiatric care provided to its residents with mental illness. We understand that the facility identified over 100 residents who are in need of review and re-consent for their psychotropic medication.

There are other concerns with how mental health services are delivered at New Lisbon. It appears that the psychiatrists have only just begun to consider resident behavioral and other data and the elements of their behavior programs in developing psychiatric interventions. In fact, earlier this year, the psychiatrists acknowledged to us that they had been relying only upon informal

"staff reports" when considering what diagnoses, treatment and monitoring were appropriate for residents with mental illness at the facility. Thus, both the psychiatrists and the psychologists told us that data-based decision-making does not occur with regard to residents' behavioral needs. This places New Lisbon residents at risk for incorrect diagnoses and prescription of incorrect medications as well as at risk for over-medication.

Finally, a large number of residents receive multiple medications for their mental illness. For example, 10 residents receive five psychotropic medications, 28 residents receive four psychotropic medications, and 80 residents receive three psychotropic medications. Thus, over 30 percent of the residents on psychotropic drugs receive three or more medications. This is of concern as most of the individuals on four and five medications have a history of high and chronic use of restraint as well as many incidents and injuries due to behavior problems. The use of polypharmacy without strong justification and intense oversight is inconsistent with currently accepted practice.

IV. HABILITATION

New Lisbon fails to provide its residents with adequate habilitation services and supports and New Lisbon's individualized planning process fails to meet current professional standards. New Lisbon's individualized habilitation plans ("IHPs") contain very few skill training objectives and do not support person-centered planning with a focus on the resident's vision for the future and outcomes for achievement. As a result, New Lisbon does not provide residents with adequate opportunities to enhance their independence or achieve their visions or goals.

One problem is that New Lisbon's interdisciplinary teams do not develop IHPs that meet current professional standards. New Lisbon's IHPs are neither comprehensive nor holistic. Rather, New Lisbon has a number of different documents in which information essential to the provision of adequate habilitation and protection from harm is maintained. This requires staff to access numerous documents in order to obtain a complete picture of the services and supports a resident requires. This is inconsistent with current professional standards which require that one holistic plan be developed and implemented to provide a roadmap of all the supports a person requires.

Another problem is that New Lisbon's IHPs do not reflect an

adequate interdisciplinary process. The IHPs developed by New Lisbon seldom address residents' preferences and contain few service objectives. Consistently, the functional assessments found in the files of New Lisbon residents contained numerous recommendations that were not incorporated into the IHPs through either a behavioral or service/support objective. Likewise, the functional assessments often identified some of the residents' preferences, but interdisciplinary teams often failed to integrate such preferences into the IHPs. In addition, teaching techniques were not described in detail and used too little positive reinforcement. As a result, these techniques are not likely to result in appropriate skill development. The IHPs need to be more individualized if learning is to occur.

In order to ensure that residents are afforded adequate habilitation, the IHPs must define in measurable terms the services and supports to be provided. In many cases, measurable objectives or outcomes are not present in residents' IHPs. For example, some residents of New Lisbon utilize alternative modes of communication such as sign language or voice output systems. However, objectives such as "John will receive speech and language services" are commonly included in New Lisbon IHPs. Such an objective fails to define the type of speech, language, and/or communication services a resident will receive, what the expected outcomes are anticipated to be, the frequency and/or duration with which such supports will be provided, and/or how the resident's team will know when such services are no longer necessary. Moreover, staff working with such residents should be proficient in these forms of communication and this should be specified in their IHPs. This does not happen at New Lisbon.

In addition, the implementation of IHPs is inconsistent and often times does not follow the written habilitation plans. This is due in part because New Lisbon fails to provide adequate competency-based training to its staff charged with teaching residents pursuant to the written habilitation plans. Some staff informed us that they received no direct instruction on how to teach pursuant to the plans, while others had to learn by simply reading the plans. As a result, we observed attempts to teach that were ineffective, did not utilize positive reinforcement, and were not likely to result in learning. In addition, there were few informal interactions between staff and residents that involved teaching a new skill. Typical components of informal teaching include instruction, modeling, feedback, practice, and reinforcement. We rarely observed these types of informal interactions between staff and residents at New Lisbon.

During our on-site visit, we also discovered a low level of engagement among the residents even though staffing was often adequate and the residents had the capability to learn. Too often, residents were not engaged and the staff did not attempt to engage them. We found several examples where nothing was happening with residents – they were all sitting idly in chairs – even though staff were present. Sometimes, the notes in the IHP would indicate that no training objectives were addressed in a given quarter due to a lack of training opportunities. This cannot be attributed to a lack of staffing alone as we found this designation even where the resident had 1:1 staffing. In other cases, certain training objectives were discontinued due to a lack of progress even though the lack of progress was not the resident's fault. Instead, the problem lies with the facility and the staff in that they provide poorly designed and poorly implemented training programs and substandard instruction. Teaching objectives should be evaluated for progress or lack of progress on a regular basis. However, at New Lisbon, it is virtually impossible to monitor progress on training objectives as data is not collected, graphs are not done, and anecdotal notes are scattered throughout the record.

New Lisbon provides a number of day program options to residents. Some of the options are good and individualized and offer stimulating work for the residents. As of May 2002, there were about 57 New Lisbon residents who attend Esteem Industries, a sheltered workshop day program on campus; another 61 residents work in the on-campus employment program doing laundry, food service work, building maintenance, and working as messengers; about a dozen additional residents work on-campus doing horticulture; three residents work in the appliance repair shop; five residents work in the recycling program on-campus; about two dozen other residents work off-campus doing various public works; and a handful of residents work in the community in supported employment situations.

Nonetheless, for many residents, the day programming may not be meeting their needs. This is because, overall, there is a lack of planning on the part of the residents' teams with regard to day program/vocational supports. For example, it does not appear that the facility is offering many residents sufficient opportunities to work off-campus in more integrated settings even though many appear capable of benefitting from more stimulating work. There are several residents for whom teams have discussed competitive employment, however, New Lisbon has not included specific measurable outcomes or objectives in their IHPs to achieve this end. Career development planning for such residents is virtually non-existent. For the vast

majority of residents who are involved in employment or other activities on campus, their IHPs fail to include meaningful training and support objectives designed to increase their independence. In addition, there are hundreds of New Lisbon residents who do not receive any off-residence day programming or vocational opportunities that would meet their needs. This is problematic because many residents are not given enough to do during the day and this can cause regression and exacerbate problematic behaviors due to boredom. Lack of transportation options also may be hindering residents' ability to go off-campus. As a result of the foregoing, New Lisbon residents do not receive the habilitation to which they are entitled.

V. HEALTH CARE

Many aspects of health care delivery at New Lisbon are acceptable. For example, the preventive health care program for residents who do not have high-risk conditions typically meets acceptable standards; health care documentation is usually timely, reasonably detailed, and accurate; facility-wide emergency care meets acceptable standards; and the clinical laboratory meets an acceptable standard. The pharmacy service exceeds acceptable standards of care.

Nonetheless, New Lisbon is failing to meet the individualized health care needs of some of its residents. This is especially true of residents with bowel obstructions and residents with nutritional and physical management concerns. In spite of the fact that the New Lisbon medical department is well-organized with good leadership, the physicians appear to have more obligations than they can handle adequately given the large number of residents with special intensive needs, with high-risk health factors, and/or who are medically complex. We understand that the State recognizes this and is actively seeking to recruit at least two additional internists to increase the availability of primary care physicians at the facility.

A. Bowel Obstructions

New Lisbon fails to provide needed proactive and preventive health care for the vulnerable population of residents with serious gastrointestinal conditions, including obstipation and intestinal obstruction, which may lead to bowel perforation and even death in this population. These serious conditions are preventable. As a result, New Lisbon fails to provide health care in this area that meets current generally accepted practice.

There are many New Lisbon residents with gastrointestinal concerns and many others at risk of developing complications from gastrointestinal concerns, including those who are not active physically. These residents are at great risk for developing chronic constipation that may lead to obstructions. Chronic constipation often leads to a cascade of troubling events which are more pronounced in this particularly vulnerable population. Milder consequences include dehydration and discomfort during bowel movements. More serious consequences include blockage in the intestines which produces cramping and an enlargement of the abdomen visible to even a casual observer. In the most serious cases, the intestines can rupture, causing blood poisoning and frequently death. Such high-risk factors demand proactive and priority involvement from health care and direct care staff. Nonetheless, such involvement is often lacking at New Lisbon.

New Lisbon residents with such high-risk health care needs are frequently hospitalized for continuing care of acute medical problems developed while residing at New Lisbon. In the three month period between January and March 2002, New Lisbon reported that seven residents had been hospitalized due to health concerns related to bowel obstruction. Similarly, in 2001, there were close to two dozen additional hospitalizations related to bowel obstructions, rectal bleeding, and a possible gangrenous bowel.

Most troubling, several New Lisbon residents have died recently following the rupture of their intestines related to the onset of a bowel obstruction. For example, last year, resident Brian suffered with prolonged abdominal pain caused by an undetected small bowel obstruction that eventually led to a bowel perforation. Specifically, Brian had a perforated ileum, collapsed colon, and three small tears in his small bowel secondary to bowel obstruction. He needed surgery to repair the perforation. In spite of the surgery, Brian died approximately one week later. New Lisbon had failed to note and recognize that in the days immediately preceding the hospitalization, Brian was not only constipated but obstipated to the point where bowel obstruction was imminent. There have been other similar cases: Ryan died following a small bowel rupture secondary to a bowel obstruction; and Jonathan died secondary to a perforated viscus (ruptured bowel).

With appropriate proactive care and monitoring, these emergencies should not have developed in the first place. There is a need to develop and implement a policy at New Lisbon that requires closer scrutiny of the clinical process preceding the onset of

symptoms leading to death in such cases so that preventative measures can be put in place to avoid future problems. Right now, New Lisbon's mortality reviews contain considerable information that is not utilized to benefit the other residents.

B. Neurology

New Lisbon fails to provide adequate neurologic health care to those residents with seizure disorders. Close to one third of the New Lisbon population – or approximately 170 residents – has a seizure disorder. Nevertheless, New Lisbon only provides a monthly total of 10 hours of time with consultant neurologists to serve the ongoing needs of this sizable population. This limited amount of time prevents the facility from providing residents who have seizure disorders with the proactive health care they require for their often complex needs and prevents the facility from serving the remainder of the client population who experience the onset of new seizures and/or other neurologic conditions.

This finding is borne out by resident outcomes. For example, a significant number of the residents who need anticonvulsant medication receive three or more medications, increasing the likelihood of adverse side effects from the medication. Moreover, from January 2002 through mid-April 2002, New Lisbon reported that five residents had been hospitalized due to health concerns with regard to seizures. In addition, in 2001, there were a variety of seizure disorder-related preventable hospitalizations including those for anticonvulsant medication toxicity and status epilepticus. We appreciate the facility's efforts in recent months to authorize the use of newer, more advanced techniques to treat seizure disorders, including the implant of Vagus Nerve Stimulators in over two dozen residents. The facility reports varied but generally positive results with this new procedure in terms of reduced seizure activity and improved resident alertness and mood, likely due to a decrease in the use of anticonvulsant medication in those cases.

C. Nutritional and Physical Management

New Lisbon fails to provide adequate nutritional and physical management services to meet the residents' individualized needs. In the absence of proper support, New Lisbon residents with dysphagia (difficulty chewing or swallowing) may suffer pain and discomfort at virtually every meal and increase the risk of aspirating food, fluid, or saliva into the lungs. These foreign elements often contain bacteria which meet no natural enemies in the lungs. This can lead

to aspiration pneumonia in some cases which can prompt hospitalization and even cause death among vulnerable residents in this population. At the very least, these residents may suffer by simply choking while eating or drinking. Persons with disabilities, of course, feel the same sense of momentary panic that others do when choking, however, their anxiety is likely magnified by the fact that they lack many of the same mechanisms we take for granted to dislodge food in the trachea. Increased anxiety or panic leaves these persons extremely vulnerable to inhaling food directly into their lungs instead of coughing it out.

There are a significant number of New Lisbon residents with nutritional and physical management problems. This includes persons who have dysphagia, gastroesophageal reflux, and other risk factors related to aspiration, as well as positioning difficulties that may impact breathing, swallowing, and digesting. For example, about two dozen residents receive nutrition through a tube with 10 of these persons receiving no nutrition by mouth. Moreover, the facility has identified well over 300 residents - about half of the total New Lisbon population - on its specialized feeding protocol list. In spite of these numbers, New Lisbon does not appear to have a good understanding of which residents are at risk in this area and it is not clear what criteria the facility uses to place a resident on the specialized feeding protocol list. As of April 2002, New Lisbon has provided almost all of these residents with a feeding/eating evaluation. However, over half these persons received the evaluation in 2002, shortly before our visit. This is significant as several residents previously had old evaluations dating back over 10 years.

The failure to provide adequate nutritional and physical management services has led to poor outcomes for residents. For example, from January 2, 2001 through May 11, 2002, there were 75 hospitalizations relating to nutritional and physical support issues from New Lisbon, such as pneumonia, aspiration pneumonia, gastrointestinal bleeding, gastroesophageal reflux, esophagitis, other gastrointestinal concerns, weight loss, anemia, dehydration, malnutrition, tube placement or related problems, dysphagia, decubitus ulcers, and respiratory distress. One problem is that New Lisbon fails to provide a coordinated and collaborative team approach to address health and medical issues, as well as to meet the functional outcome needs of a resident from a physical and nutritional support frame of reference. These include, but are not limited to: dental, nutrition, oral motor, seating, alternate positioning, and behavioral intervention. This has created increased risk of harm for residents who would benefit from these supports.

There is no proactive system at New Lisbon to identify risk indicators and convene a formalized and collaborative team review of residents who display such risk indicators. There is no mechanism or protocol for a comprehensive team review of residents who may be considered candidates for tube feeding or for the development of an appropriate support plan for residents who have received a tube due to a medical emergency or during hospitalization.

The professionals at New Lisbon, including speech, occupational, and physical therapists, provide inadequate assessments for the development of appropriate mealtime plans that include position and alignment. In addition, New Lisbon provided no dysphagia evaluations for some at-risk residents whom we observed with mealtime concerns. The facility has given responsibility for the monitoring and oversight of this population to a nutritional support team, but this team does not include the participation of a physician. It was reported that the New Lisbon physicians are too busy to participate regularly in team meetings. In addition, there is no nurse, physical therapist, psychologist, or behavioral specialist on the team. Moreover, the knowledge base of the team is at issue. Finally, in spite of compelling individual resident needs, the team has been focused primarily on the development of policies and procedures rather than on addressing individual residents' needs.

There are many practices and omissions of care we observed at mealtimes that place New Lisbon residents at risk of harm and fail to comport with generally accepted practice. For example, staff assisted residents or permitted residents to eat and/or drink independently at too fast a rate during mealtime observations. Staff presented some residents with too large a bite or allowed residents to take large bites independently without staff intervention, thereby placing the residents at risk of choking or aspiration. A number of residents coughed during the meals without adequate staff attention or intervention. Many residents ate and drank at meals in poor postural alignment which placed them at risk of choking or aspiration. Staff often did not help to realign residents properly prior to or during a meal. In some instances, staff did not follow instructions on resident meal cards. Staff served some residents food that did not match their diet order as indicated on their meal card. The therapy professionals and dieticians present in the dining rooms during meals consistently served as poor models for implementing appropriate physical assistance techniques for alignment and support, as well as for implementing appropriate mealtime strategies.

New Lisbon provides extremely limited alternate positioning options for residents for pressure relief, participation in functional skills, and therapy supports. There was little evidence that any assessment had been completed for any resident who could have benefitted from such an assessment and the alternate positioning that was provided was inadequate to provide appropriate alignment and support for function. New Lisbon fails to provide assessments at nighttime or resting bed positions for residents at risk of aspiration and gastroesophageal reflux, and the facility provides virtually no customized or specialized positioning equipment to ensure appropriate position and alignment for nighttime or bed rest. In addition, New Lisbon staff do not use appropriate physical assistance supports for residents being transferred or repositioned. In many cases, handling techniques used by staff are not consistent with generally accepted practices and place residents at risk for injury or fractures.

New Lisbon fails to complete appropriate assessments for seating systems using accepted practices in assistive technology supports and principles of seating that focus on stability, alignment and comfort. This is due in part because the facility allots insufficient time to each resident to allow for adequate assessment and because the facility fails to document evaluations properly instead relying on staff memory to guide the evaluation. The physical therapist at New Lisbon acknowledged that there was no formal assessment process in the wheelchair clinic and that the process to be undertaken is "between his ears." This is inappropriate especially given that there are over 120 residents who need some form of seating assessment. As a result, New Lisbon provides inappropriate seating systems for numerous residents. For example, we observed seating systems where the residents' legs are elevated and straight out in front of them even though many of these residents have insufficient hamstring length for knee extension. We also observed seating systems where the residents are provided inadequate support and stability for postural control and function. Many other residents suffer with sling seat and/or sling back wheelchairs which do not provide adequate support and alignment for function even when used only as a transport chair. Finally, in spite of the fact that New Lisbon claims to have a wheelchair technician review each chair and clean each chair each week, many wheelchairs are dirty and poorly maintained.

There are numerous examples of residents who have been harmed or placed at risk of harm due to New Lisbon's substandard practices. We discuss below a few representative examples (using the pseudonyms

contained in our consultant's report) that illustrate many of the findings set forth above.

- Wyatt is a New Lisbon resident with a host of health care concerns that impact his ability to eat and drink. He is at risk of aspiration and suffers with gastroesophageal reflux. He was hospitalized last year after he vomited and the staff found blood in his emesis, a painful condition often associated with reflux. Moreover, Wyatt has suffered with significant weight loss in recent years. In spite of all this, there has been no documentation of review or evaluation by the New Lisbon speech language pathologist with regard to these issues since a swallow study was completed in February 1996. There was a very brief and very limited dysphagia update put in the notes a few weeks before our on-site tour in May 2002. This evaluation, however, did not address his significant positioning and alignment needs which put him at significant risk during meals, tooth brushing, and medication administration. During meals, we observed New Lisbon staff using inappropriate assistance techniques that increased his risk of aspiration. Specifically, the staff presented food to Wyatt too quickly before he could clear the previous bite and presented rapid sips of liquids without allowing him to breathe and clear before the next sip. In addition, the staff member was trying to help Wyatt eat and drink even though his body was in poor alignment. These practices can increase the risk of aspiration and choking for a resident like Wyatt who has significant swallowing problems. More troubling, we observed staff feeding Wyatt with his head in hyperextension which can exacerbate risk of choking and aspiration. We observed him audibly breathing, gurgling, and shaking during a meal.

- Woodrow is a New Lisbon resident with a variety of risk indicators including oral motor deficits, history of coughing and nasal regurgitation at mealtimes, difficulty maintaining proper alignment in his wheelchair, history of weight loss, gastroesophageal reflux, history of upper respiratory infection, and chronic constipation. In spite of all this, no mealtime evaluation had been completed for Woodrow until recently, despite a swallow study in 1990 recommending texture and fluid modifications to prevent aspiration risks. During mealtimes, we observed Woodrow coughing and regurgitating. These problems were exacerbated by staff placing his head in poor alignment for presentation of food and fluid, and the use of inappropriate assistance techniques. Staff training for his meal plan had not

occurred since 1996.

- Marshall is a New Lisbon resident who has documented problems with swallowing, a long-standing history of weight loss, gastroesophageal reflux, pneumonia, and dysphagia. He was admitted to the hospital in April 2002 with a diagnosis of severe esophagitis and erosion and ulceration. Another hospitalization occurred about a week later for aspiration pneumonia and esophagitis. A swallow study was completed a few days later that recommended changes in his diet and gave instructions for small bites and single sips of fluid. However, there was no evidence that New Lisbon provided a follow-up speech language pathology review; there are no observations or evaluations regarding mealtimes noted; and no diet order change was documented or rationale provided for not modifying Marshall's diet to pureed as recommended in the swallow study. He had been given a swallow study in 1996, but there was no further review of Marshall's mealtime status until a dysphagia update a few weeks prior to our on-site visit. There was no indication of staff training throughout this time.

- Arnold is a New Lisbon resident who has significant and documented difficulty in swallowing. He is at risk of aspiration and choking and he has suffered significant ongoing weight loss in recent years. In spite of this, New Lisbon has failed to provide him with needed care and services to address his complex needs. A swallow study in 1996 concluded that he was at risk of aspiration and choking, yet the New Lisbon speech language pathologist failed to complete an assessment of Arnold for over six years. (Arnold's team did not even implement the recommendations of the 1996 study.) The facility completed a four sentence dysphagia "update" about a month prior to our visit, but had not completed any other evaluations for Arnold for years. There had not been an assessment for Arnold by occupational therapy ("OT") since 1985. Moreover, there was no physical therapy ("PT") assessment or wheelchair assessment. There was no evidence of a seating assessment for Arnold in spite of the fact that he slumps in his chair and needs support during mealtimes. Moreover, the staff engage in dangerous feeding practices with Arnold. During meals, we observed staff offering inappropriately large bites of food at a rapid pace which places Arnold at further risk of aspiration and choking. Staff also allowed his head to be in hyperextension during meals which significantly increases his risk for choking and aspiration of food and fluids. Finally, New Lisbon failed to

provide Arnold with sufficient supports with regard to his wheelchair as he consistently slid down his chair under his tray. As a result, it is not possible for staff to adequately align Arnold in his wheelchair for mealtimes and other activities.

D. Occupational and Physical Therapy and Communication Services

New Lisbon fails to provide its residents with adequate and appropriate occupational therapy, physical therapy, and communication services that meet the residents' individualized needs. As a result, New Lisbon residents' limbs may weaken and become thinner; their hands may become contractured; they may lose the ability to walk or ambulate; and, overall, their physical fitness may deteriorate which compromises a host of important daily functions such as breathing, digestion, and maintaining strength to fight off illness. If communication skills deteriorate or are not developed, residents cannot convey basic needs and wants and this may have an adverse impact on their health and well-being. In addition, as noted above, New Lisbon's failure to provide residents with adequate communication training and supports results in residents not receiving adequate habilitation in order to increase their independence.

New Lisbon fails to provide many residents with current evaluations with regard to OT, PT, or communication needs. In fact, some residents have never been given an OT, PT or communication evaluation at New Lisbon. There are inadequate and too few OT services offered to residents at this time. The PT services offered are also inadequate and they are reactive, not proactive, as they are somewhat limited by physician referral to address acute medical concerns or rehabilitation. Even when OT and PT services are needed at New Lisbon, there is no adequate assessment completed. Moreover, there is no thorough follow-up review of the person's current status or changes noted since the previous assessment. There is little evidence that important information is analyzed at any stage of the process to determine a person's strengths, potential for enhanced skill performance, or new skill acquisition. When recommendations for therapy intervention are made, they generally are focused on maintenance of current status rather than attaining functional outcomes for the residents. Services provided by the New Lisbon speech-language pathologists are focused primarily on mealtime supports, not on providing communication supports. Even in the few cases where communication services are provided, there is no assessment to serve as a foundation to identify strengths, potentials

and functional outcomes for the residents. With regard to all of these disciplines, it remains unclear if the New Lisbon therapy staff are unable to recognize potentials and needs for residents or whether they simply do not have time, due to low staffing levels, to assess and implement supports appropriately for residents to meet their individualized needs.

E. Oral Hygiene

A number of residents have unacceptable oral hygiene as reported in their annual dental examination. There is little evidence that the facility has provided an assessment by OT or PT and/or the speech language pathologist for the development of oral hygiene plans to address safety, positioning and alignment and other strategies to improve oral hygiene status.

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

The Americans with Disabilities Act ("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. The regulations promulgated pursuant to the ADA provide: "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 integration regulation). The preamble to the regulations defines "the most integrated setting" to mean a setting "that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." 28 C.F.R. pt. 35, App. A at 450.

In construing the anti-discrimination provision contained within the public services portion (Title II) of the ADA, the Supreme Court held that "[u]njustified [institutional] isolation ... is properly regarded as discrimination based on disability." Olmstead v. L.C., 527 U.S. 581, 597, 600 (1999). Specifically, the Court established that States are required to provide community-based treatment for persons with developmental disabilities when the State's treatment professionals have determined that community placement is appropriate, provided that the transfer is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. Id. at 602,

607. As set forth below, the State is failing to comply with the ADA with regard to placing persons now living in New Lisbon in the most integrated setting appropriate to their individualized needs.

The census of New Lisbon has remained fairly constant over the past eight years. In 1994 and 1996, the census was 713 and in 1998, it was 653. New Lisbon reports that its census increased by three dozen people to 690 residents the next year and then declined marginally to 671 in 2001. During this eight year period, New Lisbon has placed in the community an average of 31 persons per year. However, also during this period, it has admitted to the facility an average of 33 persons per year. Deaths and transfers to other State facilities account for other yearly changes.

New Lisbon's treating professionals have identified approximately 200 residents who are not currently living in the most integrated setting appropriate to their needs. In an effort to meet the needs of these residents, the State instituted and funded the Transition Initiative, a program designed to move residents into more integrated, community-based settings. In fiscal year 2001,[6] New Lisbon conducted a lottery and, from the approximately 200 eligible residents, selected 45 for inclusion in the Transition Initiative. In fiscal year 2002, a second lottery was held and another 55 residents were selected for inclusion in the Transition Initiative. Thus, in fiscal year 2001 and 2002, New Lisbon identified 100 residents that it intended to prioritize for placement in the community. At the time of our first tour in May 2002, however, only 15 of the 100 residents who were selected for inclusion in the 2001 and 2002 Transition Initiative had been placed in the community (11 from fiscal year 2001 and 4 from fiscal year 2002). The pace with which New Lisbon places residents in the community is inadequate.

One reason that might be contributing to New Lisbon's difficulty with placing residents in the community is the low amount of funding available for each resident. According to documentation from New Lisbon, the maximum amount of money a resident can receive for community services is $60,000 per year. The rate presently paid for services at the New Lisbon facility is approximately $100,000 per year. Thus, it appears that much less funding is available to residents in the community than the State makes available to

---

6 The State of New Jersey's fiscal year runs from July 1 to June 30.

residents living at New Lisbon.

The problems with transitioning residents to the community extend beyond the slow pace of placement for residents in the Transition Initiative. As noted above, New Lisbon's treating professionals have identified approximately 200 residents who are not currently living in the most integrated setting. Yet, New Lisbon is currently seeking community placement for only 100 of these residents (the residents in the Transition Initiative). It does not appear that New Lisbon is actively seeking community placements for the other approximately 100 residents.

Finally, we find the process for identifying residents who are appropriate for community placements inadequate. For example, New Lisbon's treating professionals routinely fail to assess adequately the appropriateness of residents' placement at New Lisbon; fail to identify barriers to placement in the most integrated setting and/or include action plans to address such barriers; fail to ensure that residents and their families are informed of their right to live in the community; and fail to provide education and support to the families about the community options available or that could be created.

VII. MINIMAL REMEDIAL MEASURES

To remedy the identified deficiencies and protect the constitutional and statutory rights of New Lisbon residents, New Jersey should implement promptly, at a minimum, the remedial measures set forth below:

A. Protection from Harm

1. New Lisbon shall ensure that its residents are adequately supervised by trained staff and kept reasonably safe and protected from harm and risk of harm.

2. New Lisbon shall develop and implement adequate policies and procedures with regard to incident reporting and the conduct of investigations of more serious incidents. The facility shall fully train staff and investigators in how to implement these policies and procedures. The facility shall also track and analyze trends of incidents and injuries so as to help prevent such events from occurring in the future. New Lisbon shall provide for independent investigations. Investigation reports shall include systemic recommendations to prevent future

occurrence of injury.

3. New Lisbon shall impose discipline that is appropriate for the employees involved in substantiated cases of abuse or neglect.

B. Psychological and Behavioral Services and Restraints

1. New Lisbon shall provide residents with the psychological and behavioral services needed to meet the residents' ongoing needs. To this end, the facility shall take the following steps:

(a) New Lisbon shall provide its residents who have behavior problems with an adequate behavioral assessment in order to determine the appropriate treatments and interventions for each person. This assessment shall be interdisciplinary and shall incorporate health and other unaddressed conditions that may contribute to a person's behavior.

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

(c) New Lisbon shall train the appropriate staff how to implement the behavior programs and ensure that they are implemented consistently and effectively. This shall include recording appropriate behavioral data and notes with regard to the person's progress on the program.

(d) The facility shall continually monitor the residents' progress on the programs and revise the programs when necessary to ensure that their behavioral needs are being met. This shall involve ongoing training for staff whenever a revision is required.

2. New Lisbon shall ensure that restraints are never used as punishment, in lieu of training programs, or for the convenience of staff. To this end, the facility shall take the following

steps:

(a) New Lisbon shall implement a protocol that places the appropriate limits on the use of four and five-point restraints as well as the routine use of emergency chemical and unplanned physical or mechanical restraints.

(b) For those individuals subjected to chronic use of restraints associated with difficult behavior problems, New Lisbon shall obtain outside expertise to help the facility address the persons' behavior problems in an attempt to reduce both the behaviors and the use of restraint.

(c) New Lisbon shall carefully track the use of chemical restraints and restraints used for "medical" purposes to ensure that reductions in behavioral mechanical restraints are not replaced with these kinds of restraints.

(d) The facility shall fully document and track the use of personal control and seek to significantly reduce its use among residents.

(e) New Lisbon shall work to place appropriate limits on the use of large padded helmets. If any helmets are used, the facility shall develop and implement a protocol that requires the helmets to be the least intrusive possible suited to each resident.

C. Psychiatric Care

1. New Lisbon shall provide adequate psychiatric services consistent with accepted professional standards to residents who need such services. To this end, New Lisbon shall take the following steps:

(a) The facility shall ensure that each resident with mental illness at New Lisbon is provided with a new comprehensive psychiatric assessment, a differential DSM-IV diagnosis, appropriate psychiatric treatment including appropriate medication that fits the diagnosis, and regular and ongoing monitoring of the psychiatric treatment to ensure that it is meeting the needs of each person. The psychiatrist shall provide new assessments and/or revisions to any aspect of the treatment regimen whenever appropriate. Psychiatric services shall be developed and

implemented in close collaboration with the facility's psychologists so as to provide coordinated behavioral care.

(b) New Lisbon shall procure adequate psychiatry hours to meet the needs of the residents.

(c) Psychotropic medication shall only be used in accordance with accepted professional standards and shall not be used as punishment, in lieu of a training program, for behavior control, in lieu of a psychiatric or neuropsychiatric diagnosis, or for the convenience of staff. New Lisbon shall ensure that no resident receives psychotropic medication without an accompanying behavior program.

(d) The facility shall improve the quality of behavioral and other data provided to psychiatrists to better ensure adequate psychiatric treatment for each person.

D. Habilitation

1. New Lisbon shall provide its residents with adequate habilitation services and supports that meet current professional standards. New Lisbon shall ensure that its residents receive meaningful training daily. To this end, the facility shall take the following steps:

(a) The facility's interdisciplinary teams shall identify individuals' needs, preferences and interests and develop strategies to address these needs and preferences in an integrated fashion. The facility shall ensure that this is set forth in a comprehensive interdisciplinary plan for the provision of training, services and supports.

(b) New Lisbon shall ensure that staff are trained in how to implement the written plans and that they are implemented properly.

(c) New Lisbon shall provide an assessment of all residents to ensure that they are receiving the vocational and/or day programming services that meet their individualized needs.

(d) New Lisbon shall ensure that there is sufficient transportation to enable residents to work off-campus or

attend off-campus programming.

E. Health Care

1. New Lisbon shall provide adequate medical and dental care in accordance with generally accepted standards. To this end, the facility shall take the following steps:

(a) New Lisbon shall provide adequate and appropriate routine, chronic, and emergency seizure management to all individuals with epilepsy at New Lisbon in accordance with accepted professional standards of care.

(b) The facility shall place an emphasis on providing adequate assessments and treatments for those residents with high-risk conditions such as risk for bowel obstructions.

(c) The facility shall employ sufficient physicians to meet residents' needs.

F. Nutritional and Physical Management and Therapy Services

1. New Lisbon shall ensure that its residents receive adequate nutritional and physical management services, and that professionals in these disciplines perform their responsibilities in keeping with accepted professional standards of care by adequately identifying nutritional and physical management problems, notifying physicians of such problems when appropriate, and monitoring and intervening to ameliorate such problems. In particular, New Lisbon shall develop and implement policies and protocols to provide each resident with adequate and appropriate nutritional and physical management in accordance with accepted standards of care. To this end, New Lisbon shall take the following steps:

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

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

(c) Take necessary steps to ameliorate the problems, including providing sufficient mealtime supports to meet residents' needs.

(d) Develop and implement a system to regularly monitor the progress of the residents with nutritional management difficulties to ensure that staff is continually taking whatever assessment, diagnostic, supervision, and treatment steps are necessary to ameliorate the residents' difficulties.

2. New Lisbon shall provide each resident with adequate and appropriate physical and occupational therapy services and communication services in accordance with accepted standards of care. This shall include an adequate and appropriate assessment, analysis, therapy plan, implementation of the plan and ongoing monitoring with revision of the plan and its implementation whenever necessary. The facility shall ensure that staff employ proper handling/transfer techniques for residents.

G. Placement in the Most Integrated Setting

1. The State shall provide services to individuals with developmental disabilities in the most integrated setting appropriate to their needs. To this end, 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 and to be identified as eligible for community placement; establish a schedule to place such individuals in community-based programs.

(b) Conduct an interdisciplinary assessment of each resident to determine whether the resident is in the most integrated setting appropriate to his/her needs. Assessments of new admissions should be done at admission; assessments of individuals who remain at the facility for extended periods of time should be periodically updated.

(c) If it is determined that a more integrated setting would appropriately meet the individual's needs, promptly develop and implement, with appropriate consent, 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 consent decisions are fully informed.

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

* * *

As stated earlier, 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 New Lisbon. In order to assist you in this regard, we will forward our expert consultants' reports under separate cover. Although their reports are their work - and do not necessarily represent the official conclusions of the Department of Justice - their observations, analyses, and recommendations provide further elaboration of the relevant concerns and offer practical assistance in addressing them. We hope that you will give this information careful consideration and that it will assist in your efforts at prompt remediation.

In the unexpected event that the parties are unable to reach a resolution regarding our concerns, we are obligated to advise you that the Attorney General may initiate a lawsuit pursuant to CRIPA, to correct deficiencies or to otherwise protect the rights of New Lisbon residents, 49 days after the receipt of this letter. 42 U.S.C. § 1997b(a)(1). Accordingly, we will soon contact State officials to discuss in more detail the measures that the State must take to address the deficiencies identified herein.

Sincerely,

Ralph F. Boyd, Jr.
Assistant Attorney General

cc: The Honorable David Samson
Attorney General
State of New Jersey

Gwendolyn L. Harris
Commissioner
Department of Human Services
State of New Jersey

Jeffrey Schroeder
Acting Chief Executive Officer
New Lisbon Developmental Center

Christopher J. Christie, Esq.
United States Attorney
District of New Jersey