January 4, 2006

The Honorable Arnold Schwarzenegger
Governor of California
State Capitol Building
Sacramento, CA 95814

Re: CRIPA Investigation of the Lanterman Developmental Center, Pomona, California

Dear Governor Schwarzenegger:

I am writing to report the findings of the Civil Rights Division's investigation of conditions and practices at the Lanterman Developmental Center ("Lanterman"), in Pomona, California.[1] On April 9, 2004, we notified you of our intent to conduct an investigation of Lanterman pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. CRIPA gives the Department of Justice authority to seek remedies for any pattern and practice of conduct that violates the constitutional or federal statutory rights of persons with developmental disabilities who are served in public institutions.

In October 2004, we conducted an on-site inspection of Lanterman with expert consultants in various disciplines. Before, during, and after our site visit, we reviewed a wide variety of relevant State and facility documents, including policies, procedures, and medical and other records relating to the care and treatment of hundreds of Lanterman residents. During our visit, we also interviewed Lanterman administrators, professionals, and staff, and observed residents in their

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[1] In recent years, the Department has issued many different findings letters to the State of California, pursuant to the Civil Rights of Institutionalized Persons Act, 42 U.S.C. § 1997, with regard to violations of the constitutional and federal statutory rights of residents at other state-owned and -operated facilities, including: the Agnews and Sonoma Developmental Centers and the Metropolitan and Napa State Hospitals. We are currently conducting an investigation of conditions and practices at the Patton and Atascadero State Hospitals. Finally, we have issued findings with regard to the State's contribution to violations of the Americans with Disabilities Act ("ADA") at the Laguna Honda Hospital and Rehabilitation Center.

residences, at activity areas, and during meals. In keeping with our pledge of transparency and to provide technical assistance where appropriate regarding our investigatory findings, we conveyed our preliminary findings to State counsel and to certain State and facility administrators and staff during verbal exit presentations at the close of our on-site visit.

We would like to express our appreciation to the State for the extensive cooperation and assistance provided to us throughout by officials from the Department of Developmental Services and by the Lanterman administrators, professionals, and staff. We hope to continue to work with the State and officials at Lanterman in the same cooperative manner going forward.

Consistent with our statutory obligations 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. 42 U.S.C. § 1997b(a). Specifically, we have concluded that numerous conditions and practices at Lanterman violate the constitutional and federal statutory rights of its residents. In particular, we find that residents of Lanterman suffer significant harm and risk of harm from the facility's failure to: (i) keep them safe; (ii) provide them with adequate training and associated behavioral and mental health services; and (iii)provide them with adequate health care. Youngberg v. Romeo, 457 U.S. 307 (1982); Title XIX of the Social Security Act, 42 U.S.C. § 1396; 42 C.F.R. Part 483, Subpart I (Medicaid Program Provisions). The deficiencies are evidenced through preventable injuries, illness, and death. In addition, we find that the State fails to provide services to certain Lanterman residents in the most integrated setting, as required by 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).

I. BACKGROUND

Lanterman is a state-owned and -operated residential facility for persons with developmental disabilities such as mental retardation, cerebral palsy, and autism. At the time of our visit in October 2004, Lanterman housed 582 residents aged 11 to 83. Residents live in approximately 20 residences spread across the facility's campus. At the time of our visit, about one-fourth of the residents resided in six nursing facility or acute care units located on the campus. The other 442 residents lived in residential buildings.

The Lanterman 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 Lanterman 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 such as self-injurious behavior or aggression. At the time of our visit, the facility reported that 229 residents had a behavior program and that over 15 percent of these programs included some form of restrictive component such as 4-point and 5-point restraints used on residents in chairs or in beds. In the year prior to our visit, dozens more Lanterman residents received highly restrictive interventions on an unplanned or emergency basis, outside the context of their behavior program. Over 30 percent of Lanterman residents had been diagnosed as having mental illness, and all but a handful of these residents were receiving one or more psychotropic medications.

II. FINDINGS

A. PROTECTION FROM HARM

The Supreme Court established that persons with developmental disabilities who reside in State institutions have a "constitutionally protected liberty interest in safety." Youngberg v. Romeo, 457 U.S. at 318. The Court held that the State "has the unquestioned duty to provide reasonable safety for all residents" within the institution. Id. at 324.

In our judgment, Lanterman fails to provide its residents with a reasonably safe living environment. The facility too often subjects its residents to harm or risk of harm. Lanterman residents are subjected to neglect and physical abuse and suffer a high number of incidents which often result in injuries or other poor outcomes. Resolution of these concerns is hampered by an inadequate incident reporting and investigation system.

1. Abuse and Neglect

For the period between September 1, 2003 and September 30, 2004, internal Lanterman documents reveal that there were at

least 275 incidents at the facility involving allegations of abuse or neglect against residents. This included 40 allegations of neglect or neglectful abuse, five allegations of psychological abuse, three allegations of sexual abuse, four allegations of verbal abuse, and 29 other physical abuse allegations. Moreover, there were 189 reports of resident-against-resident physical assault and five allegations of resident-against-resident sexual assault.

We highlight below a few examples where internal Lanterman investigations confirmed abuse or neglect allegations, demonstrating, in part, the facility's failure to protect its residents from harm.

- The most horrifying incident in recent years occurred on August 7, 2002, when resident A.Z.[2] died from multiple blunt force trauma after being stomped repeatedly in his bedroom at Lanterman. There were two suspects in the investigation -- A.Z.'s roommate and a facility Psychiatric Technician. Although there was evidence pointing to both suspects, the investigator concluded that the roommate had committed the crime, but was too mentally impaired to face any charges. Regardless of who was responsible, the fact that A.Z. suffered severe pain and ultimately died at Lanterman in spite of the State's obligation to keep him safe is deeply disturbing.

- In January 2004, an internal investigation confirmed abuse after concluding that a Lanterman staff person had punitively tied the hands of resident M.N. behind his back on two separate occasions. One of these times, the staff person had placed a chair on top of M.N. and sat on the chair while M.N. lay on the floor with his hands bound.

- In February 2004, an internal Lanterman investigation confirmed that Lanterman staff had neglected five residents with incontinence concerns. The staff person on duty left these residents alone in a room and had gone to lunch without ensuring that the needs of the residents were met, or that someone else was supervising them. Another Lanterman staff person later found these residents and all five had urinated on and/or soiled themselves.

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[2] In order to protect the identity of residents, we use coded initials throughout this letter. We will transmit separately a schedule cross-referencing the coded initials with the actual names of the residents.

- That same month, a separate internal Lanterman investigation confirmed that facility staff had neglected female resident B.Y. after allowing her to sit in the hallway by the nurses station for 30 minutes, at times naked, and at other times in some state of undress, often masturbating. The internal investigation confirmed a second finding of neglect due to the fact that this resident's team had been aware that she regularly engaged in public masturbation, but did not document these behaviors in her plan, or develop or implement a plan to address them.

- On May 18, 2004, Lanterman staff placed resident L.O. in an inappropriate shower chair. The resident slipped and suffered a laceration above her right eyebrow area. The internal facility investigation of the incident resulted in a finding of abuse and neglect. The staff member responsible had been involved in three prior incidents where a resident in his care was injured in the shower. One of these other incidents involved the same resident.

- A similar incident occurred in September 2003. An internal Lanterman investigation confirmed neglect against a staff member who had dropped resident C.X. while transferring him from his wheelchair to a shower chair. The resident suffered a fracture of his leg due to the improper handling by the staff.

2. Incidents and Injuries

Lanterman reports reveal that residents regularly experience harm and risk of harm in their day-to-day lives. Facility records indicate that for the period between September 1, 2003 and September 30, 2004, there were a total of 1,681 incidents at Lanterman. While some of these incidents were relatively minor, others were very serious and produced grave injuries. Of the 471 injuries during this time period, at least 233 were lacerations, and 61 of these required sutures. In addition, between September 1, 2003 and October 30, 2004, Lanterman residents suffered at least 67 fractures.

It is unclear how so many serious injuries can occur at a facility that is supposed to provide residents with a heightened level of care and supervision. Most troubling, perhaps, is the high number of injuries and incidents among residents that the facility categorizes as of "unknown" origin. In general, a significant number of unknown incidents at an institution suggests an unsafe environment and one where supervision is

inadequate to protect residents from harm. At Lanterman, internal documents reveal that between September 1, 2003 and September 30, 2004, there were at least 764 incidents of unknown cause, representing almost half of all incidents recorded during that period. As we discuss in greater detail below, it is telling that Lanterman was unable to determine the cause of injury over three-fourths of the time when residents suffered a fracture at the facility.

Unfortunately, some residents have suffered multiple injuries that illustrate a variety of safety concerns at Lanterman. For example, resident K.P. sustained 17 injuries between January 1, 2003 and September 30, 2004, including seven lacerations, four incidents of swelling on her face or eyes, four incidents of bruising, and two incidents of scratches and abrasions. Resident D.B. sustained 14 injuries between September 1, 2003 and September 30, 2004, including one incident in which she fractured her wrist. The cause of half of her 14 injuries is unknown; three were a result of being attacked by other residents, and three were caused by self-injury. Despite this resident's history of being at high risk for injury and her clear inability to identify or avoid potentially harmful situations, we observed staff leave her unsupervised at her residence. When asked, staff acknowledged that this resident was supposed to be provided with "close supervision."

a. Fractures

In the year before our visit, dozens of Lanterman residents suffered fractures. Many of these fractures appear to have been preventable. Moreover, as referenced above, it is problematic that over three-fourths of the time, Lanterman did not know how the fracture happened. We set forth below a few examples of residents who suffered fractures at Lanterman in the months prior to our visit.

- Lanterman staff discovered resident J.Q. with a broken jaw. The facility was unable to determine the cause of this fracture. In fact, staff only became aware of his injury when they noticed that Mr. Q. had blood dripping from his mouth onto his shirt, pants, and fingers. It appears that staff did not adequately supervise this resident, who was known to engage in behaviors that placed him at risk.

- Staff neglect caused resident U.E. to fracture one of his vertebrae. An internal Lanterman investigation substantiated neglect because staff had left the resident in his bedroom unattended while he was in an agitated state.

It appears the resident must have tried to get out of his wheelchair on his own when no staff were present. When staff later found the resident, he was “breathing poorly and [appeared] dusky in color because the seatbelt [from his wheelchair] was constricting his neck.” The physician sent him for x-rays, which revealed that he had fractured one of his vertebrae.

- Improper staff intervention caused resident I.R. to fall out of a chair and break his collar bone. At the time, the resident was being treated with morphine for pain management. Even though staff members were aware that the prescribed morphine could make him drowsy, they nonetheless placed him in a straight-back chair that did not offer the proper support. Mr. R. fell out of the chair, breaking his collar bone.

- Resident F.V. sustained a fracture of his leg. Although the cause of the fracture is listed as unknown, Lanterman staff suspect that it occurred while staff were repositioning him. It was only after the resident experienced the fracture that staff were taught the proper method for repositioning him.

- Resident H.S. broke his toe. This is the most recent in a series of fractures the resident has suffered. In 1991, Mr. S. also fractured a toe, in 1995 he fractured his wrist, and in 2002 he fractured his clavicle. Nonetheless, it was not until his most recent fracture in April 2004, that the facility recommended that he undergo a bone density test to determine if he had osteoporosis. In June 2004, the test revealed that he has osteoporosis and is at high risk for fractures.

- Facility staff discovered two different residents, G.T. and X.R., with broken ribs during routine medical evaluations and determined that the causes of these fractures were unknown.

- Facility staff discovered three residents -- L.F., W.Q., and K.B. -- with broken clavicles but they were unable to determine the causes of the fractures.

In January 2004, the facility established a fracture committee to address the high number of fractures among residents. This is a positive development. This committee reviews each fracture that occurs and makes recommendations, as appropriate. The committee has begun to look at trends and behavioral issues that might increase the risk for fractures.

Although this group has made some progress, the coordinated effort needed to reduce the number of preventable fractures is not yet in place at Lanterman. Residents are still at high risk for fractures. For example, most of the fracture committee's response to ongoing issues is largely reactive. Committee members acknowledge that they generally recommend training for staff only after a fracture has occurred. Residents should not have to wait until they suffer a fracture before their staff workers are properly trained. Moreover, the efficacy of some of this training is questionable because it is not competency-based. The committee relies heavily on passive training videos rather than on providing active, hands-on technical assistance from a therapist or other competent individual to help identify and correct problems with the staff's intervention methodologies. In addition, the committee still needs to address inadequacies with regard to the supervision of residents and needs to coordinate better with psychology staff to implement adequately residents' behavioral supports.

b. Lacerations Requiring Sutures

Between September 1, 2003 and September 30, 2004, Lanterman residents suffered a total of more than 230 lacerations at the facility; at least one-fourth of these lacerations required sutures. We set forth below a few examples of residents who suffered lacerations in the months prior to our tour.

- A few residents have suffered disturbing lacerations in the genital area. For example, resident V.P. sustained a laceration of his scrotum that required five sutures. Another resident, D.J., sustained a laceration of his scrotum requiring eight sutures to close. The cause of D.J.'s injury is officially listed as unknown, but it appears that it occurred while staff members were assisting him after he had a bowel movement.

- In spite of the fact that resident U.O. requires ongoing supervision, facility staff allowed her to leave her residence, unsupervised, through a door that staff had not properly secured. She fell and sustained a number of injuries, including a laceration to her forehead that required four sutures, a laceration in her mouth that required two sutures, and several loose teeth, including one that had to be pulled. According to facility assessments, U.O. lacks safety awareness and is at risk for falls and fractures.

- Resident I.C. fell off of a couch, hit her head, and sustained a laceration requiring two sutures. This resident requires one-to-one supervision “due to her unsteadiness and history of falls,” yet her one-to-one staff person was not with her to prevent or break the fall.

- After staff members had failed to re-direct resident T.N. from banging on the walls, the resident put his hand through a window causing multiple lacerations, one of which required three sutures.

Lack of adequate staff supervision, environmental and safety concerns, as well as a failure to provide adequate behavior supports all contribute to an increased risk of harm for many residents on a day-to-day basis. They also appear to contribute to a significant number of peer-to-peer altercations at Lanterman, many of which produce lacerations. We set forth below illustrative examples of this pattern.

- Resident H.B. sustained a laceration near his temple that required three sutures to close. A peer hit him in the head with a fist in retaliation after H.B. had initially grabbed the peer’s arm.

- Resident S.M. sustained a laceration requiring five sutures after a peer struck him on his lower lip.

- Two female residents, G.A. and R.B., were involved in an altercation during which each bit the other. One woman sustained a laceration requiring four sutures. Both of these women require “close” supervision because each has a history of being aggressive toward others. However, it appears that when this incident occurred, staff had left the two residents virtually unsupervised.

3. Incident Reporting, Investigations, and Follow-Up

We identified a number of problems with the facility’s incident management system. Incidents are not consistently categorized at Lanterman. We also found that important incident reports are not accounted for in the tracking system. Moreover, in reviewing documents provided by the facility, we identified instances in which staff failed to report incidents in a timely manner in violation of mandatory reporting requirements. This discovery raises concerns about whether or not other important incidents are being reported on time or at all. As a result, we do not have confidence that the incident information recorded and reported at Lanterman accurately reflects all of the reportable

incidents that actually occur at the facility. Given these failures, the incident and injury numbers we set forth above may, in fact, under-represent the harm that actually occurred at the facility. Finally, we have concerns with regard to the adequacy of certain incident investigations. We describe our concerns with Lanterman's incident reporting, investigations, and follow-up system in greater detail below.

- Lanterman's policies and procedures related to reporting and categorizing incidents are disjointed, uncoordinated, and confusing. The facility provided us with draft revisions to the State's incident management policy that appear to include an improved classification system for incidents. This document appears to attempt to define incident types more specifically.

- The facility provided us with several internal documents that reported different and conflicting numbers of resident fractures that had occurred during a set period of time at Lanterman. Staff acknowledged that fractures were being categorized and recorded differently in different parts of the facility's database. This makes tracking and trending such incidents unreliable, which further impairs the facility's ability to develop and implement individual or systemic remedial measures. Given the large number of fractures occurring at the facility, it is essential that management staff have reliable data sources that will allow them to review trends and analyze and address the underlying causes of all fractures.

- It is difficult to determine the exact number of choking incidents due to the facility's inconsistent methodology for reporting and categorizing these often serious events. Sometimes choking incidents at Lanterman are categorized as "injuries," and at other times they are categorized as "endangering health and safety." This ambiguity creates a risk that significant instances of choking will not be recognized as such and investigated properly. It also makes tracking and trending such incidents more difficult and impairs the facility's ability to develop and implement critical remedial measures as needed.

- Staff often do not report significant events in a timely manner. For example, the internal investigation that confirmed staff abuse against resident M.N., referenced above, revealed that the staff member who reported the abuse had not done so in a timely manner, in violation of the mandatory abuse reporting law. In fact, because of the

delay, the reporting staff member could not remember the dates on which the abuse incidents actually had occurred. Of course, with the passage of time, not only will the memories of staff and residents become less reliable, there is also a greater likelihood that evidence will be lost or destroyed, further compromising the ultimate findings of the investigation. There are other examples. For instance, the internal investigation of numerous sexual assault allegations by resident I.A. determined that these allegations had not been reported as staff became aware of them. Rather, these issues were revealed only when a staff person was conducting a review of the perpetrator's chart and talking with staff about other issues. Such delayed reporting impairs Lanterman's ability to conduct an adequate investigation with adequate and timely follow-up.

- Investigations conducted by program staff often lack the necessary components of a valid investigation. For instance, these investigations often fail to reconcile evidence appropriately, fail to include interviews of all relevant staff and residents who may have information about the incident in question, and fail to determine the cause of serious incidents. Inadequate investigations make it difficult for the facility to identify, develop, and implement corrective measures to eliminate preventable risks to residents.

- Lanterman documents reveal that many corrective measures that were supposed to be implemented to prevent future incidents are not being implemented in a timely manner. For example, the semi-annual incident report trend analysis for January 1, 2004 through June 30, 2004 showed that Program 1 had implemented only 25 percent of its corrective measures, Program 2 had completed 81 percent, Program 3 only 56 percent, and Program 4 only 67 percent. These failures place residents at ongoing risk of harm.

At the time of our tour, Lanterman had begun some quality improvement activities associated with resident incidents. For example, the facility had just undertaken some efforts to ensure that staff report all incidents, emphasizing that staff are to report even minor scratches and bruises. This is positive and should be continued. In addition, Lanterman had recently divided one residence into two to decrease the number of residents living together. It appears that this has resulted in a reduction in the number of resident incidents. Nonetheless, Lanterman's quality improvement efforts in general remain largely disjointed. For example, quality improvement staff do not regularly confirm

that remedial actions have been implemented, and that such actions have had the effect of actually correcting identified problems. Overall, the quality improvement program has continued to fail, in any type of consistent and adequate way, to track and analyze trends and problematic areas; identify preventative or corrective actions; and ensure that the implementation of such actions resulted in the improvement of outcomes for residents.

B. TRAINING AND BEHAVIORAL SERVICES, RESTRAINTS, AND PSYCHIATRIC CARE

The Supreme Court has concluded that for persons with developmental disabilities residing in State institutions, there is a constitutional right to "minimally adequate training." Youngberg v. Romeo, 457 U.S. at 322. Specifically, "the minimally adequate training required by the Constitution is such training as may be reasonable in light of [the institutionalized person's] liberty interests in safety and freedom from unreasonable restraints." Id. and at 319 ("respondent's liberty interests require the State to provide minimally adequate or reasonable training to ensure safety and freedom from undue restraint").

At the time of our tour in October 2004, approximately 229 Lanterman residents with behavior problems received training and associated psychological and behavioral services through a formal behavior program. Nonetheless, Lanterman fails to provide training and services that are adequate and appropriate to meet the needs of these residents. This deficiency contributes to poor resident outcomes, including poor progress in treating problem behaviors, increased risk for highly restrictive interventions, increased risk for injury and abuse, and decreased opportunities for placement in the most integrated setting. Inadequate training and psychological services are contributing factors to many of the incidents and injuries discussed above, which often stem from residents' inadequately addressed problem behaviors such as self-injurious behavior, aggression, or "pica" (ingesting inedible objects).

Two Lanterman residents serve as poignant examples of the poor outcomes that can result when training and associated behavioral services fail to meet resident needs:

- H.A. is a 27-year-old man who was admitted to Lanterman at age 13 for treatment of his behavior problems. However, it does not appear that the facility has made much, if any, progress in addressing his behaviors over the past 14 years. During his stay at Lanterman, he has developed serious self-

injurious behavior, such as hitting his head. Through self-injury, H.A. recently detached the retina in one of his eyes. Between January and October 2004, as a result of his uncontrolled behaviors, he also suffered seven other significant injuries. Prior to the hospitalization for his detached retina, H.A. averaged between 139 and 357 episodes of self-injurious behavior each month. Between January and October 2004, staff imposed 5,644 highly restrictive interventions on him. (We discuss highly restrictive interventions in greater depth below at § II.B.5.) His behavior program includes the use of a helmet and arm splints. He also receives three separate psychotropic medications. Despite the magnitude of his injuries and the high rate of use of highly restrictive interventions, Lanterman failed to update or change his behavioral assessment or behavior treatment plan at any time during this period. Generally accepted professional standards mandate that this should have occurred. Moreover, his team has not recommended H.A. for placement in a more integrated setting because of his high rate of uncontrolled behaviors. Thus, the facility's failures may be prolonging his behavior and may be denying him access to placement in a more integrated setting.

- C.R. is a 33-year-old man who also was admitted to Lanterman for treatment of his behavior problems. However, review of his behavioral data reveals that he has made little progress at Lanterman in learning how to control his self-injurious behavior. Severe self-injurious head-banging appears to be his most pronounced behavior problem at this time. Over the course of the past year, C.R. averaged close to 200 episodes of self-injury per month. Between January 2003 and October 2004, he suffered 10 separate serious injuries. His behavior program provides for the use of a helmet and 4-point or 5-point restraint. Between January 2003 and October 2004, staff imposed 1,841 highly restrictive interventions on him, including extended periods where he spent most of the hours of the day in restraints. He also receives two psychotropic medications. Once again, despite the magnitude of his injuries and the high rate of use of highly restrictive interventions, Lanterman never updated or changed his behavioral assessment or behavior treatment plan at any time during this period. Nor does C.R.'s team appear to have ever recommended him for placement in a more integrated setting because of his uncontrolled behaviors.

In spite of our overriding concerns, which we discuss in detail below, there are a few adequate elements in this service

delivery area. For example, psychologist caseloads are manageable at Lanterman, with some psychologists appropriately having smaller caseloads in units where there is a higher concentration of residents with more intensive problem behaviors. In addition, the behavioral assessment process to identify target behaviors is generally adequate. The facility appropriately defines, measures, and summarizes residents' target behaviors that are the focus of treatment in formal behavior management programs. The facility has put in place practical methods for recording target behaviors in both the day programs and living units, and this data is summarized and reviewed at relevant treatment planning and review meetings. Finally, the review process for treatment approval and application of restrictive interventions is consistent and followed in a timely manner.

Nonetheless, Lanterman is unable to deliver the essential aspects of needed training and psychological services to Lanterman residents because of significant core deficiencies. First, Lanterman fails to assess individual behavior problems adequately; second, the facility fails to develop and implement adequate behavior programs based on these assessments; and third, Lanterman fails to monitor and follow-up adequately enough to ensure that the programs are working on an ongoing basis. All this leads to poor outcomes among residents such as increased or unchecked behaviors, inappropriate use of medication or restraints, and failure to transition appropriate residents to more integrated community settings. We set forth below our findings in this regard in greater detail.

1. Inadequate Functional Analyses of Problem Behaviors

Prior to the initiation of psychological treatment, generally accepted practice mandates that facilities such as Lanterman conduct an adequate functional analysis.[3] The

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[3] A "functional analysis" is a professional assessment technique that relies on a detailed experimental analysis of a person's behavior. The main purpose of a functional analysis is to identify which event(s) or antecedent(s) prompts certain behaviors. The goal is to identify the particular positive or negative reinforcement variables that prompt or maintain a challenging behavior for a given individual. 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 an informed understanding of the cause of behaviors,

functional analyses at Lanterman substantially depart from accepted professional standards and thus pose a significant threat to the integrity of the entire behavioral treatment program. In fact, in all but one of the many cases we reviewed at Lanterman, the functional analysis was inadequate. This is especially significant given that half of the cases we reviewed were selected by Lanterman psychologists as examples of the best application of psychology services on their caseloads.

Contrary to generally accepted professional standards, the Lanterman functional analyses contain only broad narrative comments about presumed reasons that a resident is behaving in a certain way. The presumptions are not based on meaningful data. In the vast majority of cases, old, incomplete data is used to make vague statements about factors that maintained problem behaviors. This does not allow for the development of individualized, focused behavioral therapies that directly address the given problem behavior. Finally, there was little evidence that the functional analyses had been revised or updated appropriately, despite the fact that in many cases, there was clear evidence of a change in behaviors, an increase in the use of restrictive interventions, or a lack of progress with regard to achieving behavioral objectives through the existing program. This is troubling as there is evidence during our review period of ongoing and recurrent poor outcomes among residents, including injuries, fractures, and chronic use of restraint, all associated with problem behaviors.

Independent conclusions made by an external consultant retained by the State confirm our findings. During the review period, a consultant for the Columbus Organization conducted an independent functional analysis of more than two dozen Lanterman residents with behavior problems. In most cases, the results of the consultant’s functional analyses differed markedly from the existing functional analyses in the residents’ charts. In several cases, the consultant made explicit recommendations for more comprehensive and up-to-date functional analyses.

The Lanterman psychologists seemed to acknowledge that their methodology for conducting functional analyses could be improved. Each of the psychologists interviewed informed us that they relied primarily on informal functional analysis procedures. They added that they would welcome additional training on other methods for conducting a proper functional analysis. Part of the problem may be that Lanterman’s behavior management policy does

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attempted treatments may be arbitrary and ineffective.

not contain procedures for conducting or reporting a functional analysis consistent with generally accepted professional standards.

2. Inadequate Behavior Programs

All of the behavior programs we reviewed substantially departed from generally accepted professional standards. Again, this is significant because half of the programs we reviewed were specially selected by Lanterman psychologists as examples of good programs.

None of the programs we reviewed contained a formal replacement behavior training component to teach the resident an acceptable means of responding to situations which tend to provoke problem behaviors. Teaching replacement behaviors is a critical component of any behavior program that deals with difficult target behaviors. This does not comport with generally accepted practice.

Moreover, none of the programs we reviewed that contained an approved use of a highly restrictive intervention (discussed in greater detail below) included documentation that provided a rationale for the restrictive intervention supported by appropriate data. The use of such highly restrictive interventions is atypical for persons with developmental disabilities. Indeed, restraints can pose a significant risk of injury to them. As a result, it is necessary to have sufficient data justifying their use from either a formal functional analysis or from a previous treatment trial with a less restrictive intervention. It is troubling that such data-driven justification was lacking in the programs we reviewed.

In general, the information contained in residents' behavior programs was quite limited, regardless of the complexity of the interventions listed. For example, there was no difference in programmatic detail between the programs that contained mildly restrictive interventions and those that contained multiple, highly restrictive interventions. In fact, all of the behavior programs we reviewed lacked sufficient individualization, as we found that the particular treatment procedures for a given target behavior were generic and appeared to be copied from one resident chart to the next. All this reflects the lack of a measured, considered, and individualized approach to addressing residents' more difficult problem behaviors.

Lanterman also fails to provide adequate peer review of behavior programs, especially those with a restrictive component.

Peer review, which is an independent, outside review by peer professionals in an effort to infuse accountability into any process, helps ensure that the treatment programs developed comport with accepted professional standards. The current review process, through the facility's Behavior Support Committee, does not provide for this. Failure to provide peer review often results, as it has at Lanterman, in poor program development and implementation that impedes progress and places residents at risk of harm due to unchecked behaviors.

The State's consultant made similar findings. For example, the consultant recommended significant changes in the written behavior programs to ensure that proposed interventions are functionally based; the addition of an explicit reinforcement and/or replacement behavior training procedure; and the inclusion of detailed procedures for preventing behavioral episodes to decrease the need for restrictive interventions.

3. Poor Program Implementation, Monitoring, and Follow-Up

Consistent and correct implementation of adequate and appropriate behavior programs is required if progress is to be made on the behavior programs. Of course, as stated above, the programs themselves are deficient. Nonetheless, even the attempted implementation of these faulty programs is inadequate. Staff at Lanterman fail to implement properly the formal written behavior programs for the residents. This is a pervasive problem that implicates staff across all shifts and settings. Poor implementation of programming places Lanterman residents with behavior problems at risk of continued harm, continued exposure to restrictive intervention procedures, and continued institutionalization.

Lanterman fails to provide its staff with adequate competency-based training to properly implement behavior programs. In all of the cases we reviewed, the behavior programs failed to specify the procedures needed to train direct care staff how to implement the behavior programs. This is troubling because the behavior programs at Lanterman involve multiple distinct steps or procedures. Such complexity requires that staff demonstrate competency in order to make implementation efforts meaningful and effective for the residents. Our on-site observations and interviews with direct care staff and other staff who were responsible for implementing the written behavior programs revealed that few, if any, knew how to properly and effectively implement the programs. Indeed, about three-fourths of the staff we interviewed revealed significant errors in their

recall of basic and essential elements of the behavior programs. This included not knowing the residents' specific target behaviors and not knowing the specific interventions or restrictive procedures to use when the behavior occurred. Staff stated that they had 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. Our interviews with the Lanterman psychologists confirmed that they did not provide the staff with competency-based training. These psychologists informed us that they had some concerns with the staff's implementation of the programs they write.

Lanterman fails to monitor implementation efforts adequately. Not one of the behavior programs we reviewed specified the procedure needed to monitor staff implementation of the behavior programs. Instead, we found that the Lanterman psychologists used a variety of informal methods for monitoring that did not include documentation of whether the prescribed treatment procedures were used. This practice limits the ability of the psychologist to determine if programs are being implemented correctly.

The facility also lacks 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 the provision of training and associated psychological services at Lanterman, such as the use of restraints, the use of emergency procedures, the development and update of functional analyses, and staff implementation of programs.

Without proper quality assurance, monitoring, and follow-up, and without the assurance of adequate staff competencies, it is difficult to discern if a given resident's lack of progress in addressing problem behaviors is due to a change in his or her clinical status, due to a poor functional analysis, due to a poor behavior program, or due to poor program implementation and follow-up. As a result of these deficiencies, Lanterman residents are at continued risk of harm.

4. Poor Resident Outcomes

The aforementioned deficiencies in the development, implementation, and monitoring of behavior programs appear to have produced adverse outcomes for Lanterman residents with behavior problems. For example:

- In over half of the cases we reviewed, there was no significant or sustained progress in reducing the rate of the residents' problem target behaviors. In some cases, the rate of problem behaviors increased. This suggests that the behavior programs as implemented had been ineffective. It is troubling that in most cases, there was no evidence that changes had been made to the behavior programs along the way to address the lack of progress even though many of these residents suffered significant events that would normally prompt a revision or an update.

- As a result of the failure of behavioral training at Lanterman, the residents with problem behaviors, as well as those in their proximity, remained at risk of harm due to the consequences of the unchecked problem behaviors. Indeed, in 45 percent of the cases we reviewed, actual harm resulted from training deficiencies – either to the person with the problem behavior (e.g., from self-injury), or to others (e.g., from aggression).

- Because problem behaviors continue, these residents are then subjected to other means of control such as chemical restraint and the use of highly restrictive interventions such as emergency mechanical restraints. (We discuss in greater detail immediately below the use of restraints and the legal context in which they are viewed.) Indeed, during the review period, 54 Lanterman residents were subjected to the emergency or unplanned use of highly restrictive interventions because of their unchecked problem behaviors. Emergency restraints appear to be a ready default for staff when planned behavioral programs prove ineffective.

- The facility's failure to address adequately residents' problem behaviors makes it more difficult for many of these residents to transition to more integrated community settings. The individualized habilitation plans of some residents reveal that interdisciplinary teams at Lanterman appear reluctant to recommend a resident for placement in a more integrated community setting if the resident has significant problem behaviors. This is tragic because many residents were transferred to Lanterman for the sole purpose of ameliorating their problem behaviors.

5. Restraints

The Supreme Court has recognized that the right to be free from bodily restraint is the "core of the liberty protected by the Due Process Clause from arbitrary governmental action."

Youngberg v. Romeo, 457 U.S. at 316 (citing Greenholtz v. Inmates of Neb. Penal and Corr. Complex, 442 U.S. 1, 18).[4] See also 42 C.F.R. § 483.13(a)(resident "has the right to be free from any physical or chemical restraints ... not required to treat the resident's medical symptoms.").

The behavior management procedures at Lanterman are very restrictive and pose significant risk of injury to Lanterman residents. These highly restrictive interventions include: mechanical restraint devices that involve 2-point (arms or legs), 4-point (arms and legs), or 5-point (arms and legs and head or neck) restraints, often utilized in restraint chairs; helmets; arm splints; padded mittens; leg and arm braces; wheelchair belts and other related wheelchair restraints; and seclusion and time-out procedures. All of these interventions may be used either on a planned or on an emergency basis. The facility staff also engage in the highly restrictive practice of personal restraint, including the dangerous practice of prone personal restraint, which involves non-mechanical restrictions by staff such as physical holds and lying on top of residents on the floor. From September 1, 2003 to September 30, 2004, Lanterman staff used prone restraints on eight different residents. The use of prone restraints on persons with developmental disabilities poses a significant risk of injury and, in some cases, puts the residents in danger. See, e.g., Eric M. Weiss, Deadly Restraint: A Nationwide Pattern of Death, Hartford Courant, Oct. 11, 1998, at A1.

Consistent with generally accepted professional practices, restraints are to be included in a behavior program only when justified by the results of an adequate functional analysis and only when there is evidence that less restrictive procedures have been proven ineffective or are unsafe. As discussed above, however, functional analyses at Lanterman are inadequate, and the facility fails to adequately demonstrate that other less restrictive procedures are ineffective or unsafe before resorting

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[4] The Supreme Court has held that this interest is fully applicable to individuals with developmental disabilities who are confined to State institutions. See Youngberg, 457 U.S. at 316. The Court noted that the State is under a duty to provide an institutionalized person with a developmental disability with reasonable training "to ensure his safety and to facilitate his ability to function free from bodily restraints. It may well be unreasonable not to provide training when training could significantly reduce the need for restraints or the likelihood of violence." Id.

to highly restrictive interventions. For the period January to June 2004, 41 residents had programs that included the planned use of highly restrictive interventions. In addition, during this period, 54 residents received highly restrictive interventions on an emergency or unplanned basis outside the context of their behavior program. The administration of emergency or unplanned restraints on such a large number of residents typically reveals systemic failures in the provision of behavioral and/or other supports such that the residents are receiving unacceptable and inadequate treatment.

According to internal Lanterman quality assurance documents, during the first six months of 2004, there were 10,459 uses of highly restrictive interventions at the facility. (Prorated for the full year, this amounts to approximately 21,000 highly restrictive applications.) This six-month total includes almost 900 instances where staff subjected residents to highly invasive 2-point, 4-point, or 5-point restraints. The large number of restraint applications reveal serious, systemic concerns. Many of these restraint incidents involved staff tying the residents to a chair. During this period, Lanterman documents reveal that there were also 4,399 incidents involving the use of padded mittens or arm splints; 3,811 incidents involving the use of a helmet or a helmet with a face-guard; and 16 incidents involving the use of seclusion or time-out.

For the larger period of September 1, 2003 to September 30, 2004, there were about 75 Lanterman residents subjected to a highly restrictive intervention. A few of these residents were restrained only once during this period, while others were restrained virtually every single day for much of the day. The facility provided us with over 360 pages of restraint logs for this period documenting almost 16,000 individual uses of highly restrictive interventions. During this period, nine residents were subjected to approximately 860 highly invasive 4-point restraints or 5-point restraints. Residents were kept in these restraints for between five minutes and over three hours at a time, with most appearing to be in restraints for between 20 and 50 minutes. It was not unusual to subject the same resident to multiple applications of 4-point or 5-point restraint in a single day.

Certain residents are subjected to disturbingly frequent use of highly restrictive interventions. For example, from January 1 to October 4, 2004, resident H.A. was subjected to 5,644 applications of highly restrictive interventions, R.O. was subjected to 1,886 restraint applications (up from 437 in all of 2003), J.P. was subjected to 1,632 restraint applications (a

higher rate of restraint application from her 2003 total of 1,999 restraint applications), C.R. was subjected to 1,036 restraint applications (up from his 2003 total of 865 restraint applications), and D.E. was subjected to 862 restraint applications. The undue use of restrictive interventions among these residents is grossly excessive and constitutes a substantial departure from generally accepted professional standards pursuant to Youngberg.

In addition to the highly restrictive interventions discussed above, in contrast to generally accepted professional standards, Lanterman subjects certain of its residents to the emergency or unplanned use of psychotropic medication. It is generally accepted that these are often called "chemical restraints." From September 1, 2003 to September 30, 2004, Lanterman subjected over 40 residents to a total of 590 chemical restraints. Even more concerning, some residents received multiple applications. For example, during this period, D.E. received over 125 chemical restraints, I.S. received close to 100 chemical restraints, T.T. received over 60 chemical restraints, H.O. received over 40 chemical restraints, L.K. and J.Q. each received close to 30 chemical restraints, and I.E. had 20 chemical restraints.

Overall, the excessive use of restrictive interventions at Lanterman is inappropriate, places residents at significant risk of harm, and constitutes a substantial departure from generally accepted professional standards pursuant to Youngberg. Their use also reveals the failure of Lanterman behavior programs which should be effective in addressing the underlying cause of residents' problem behaviors. It is not acceptable simply to substitute highly restrictive interventions for ineffective behavior programs because highly restrictive interventions generally do not improve problem behaviors.

Lanterman now appears to recognize its problem with undue and chronic restraint use. We understand that the facility has initiated a number of recent steps to reduce the unnecessary use of restraints in some cases. Unfortunately, it appears that this effort was only begun in the months immediately prior to our tour. Thus, it is too early to tell if this effort will be sustainable or even successful.

6. Habilitation, Vocational Activities, and Day Programming

Lanterman also fails to provide its residents with adequate habilitation training and related vocational and day program

services and supports. During our visit, we discovered a low level of staff interaction with the residents throughout the day. Too often, residents were not engaged, and the staff did not attempt to engage them. We found several situations where nothing was happening with residents even though staff were present. We found few habilitative training and educational materials on the living units and, overall, we found a lack of a planned approach to resident training. This lack of meaningful training and activity can set the stage for the residents to engage in harmful behaviors.

Generally accepted practices mandate that persons with developmental disabilities receive services such as day programming in integrated settings wherever possible so that they may acquire new skills, grow and develop, and enhance their independence. See also Americans with Disabilities Act, 42 U.S.C. § 12132, and the requirement that services be provided in the "most integrated setting." Specifically, federal law requires that:

> Each client must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services ... that is directed toward - [t]he acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and ... [t]he prevention or deceleration of regression or loss of current optimal functional status.

42 C.F.R. § 483.440(a).

The State recognizes this in the vision statement and goals contained within its departmental Strategic Plan for persons with developmental disabilities. The State's Plan provides:

> People are [to be] part of the mainstream community and live, work and/or play and carry out daily activities in natural, integrated community and home settings ... People are [to] have places to go during the day that increase their productivity, independence and inclusion into the community ... develop alternative community-based models [] to serve individuals currently residing in state developmental centers ... Enhance people's opportunities for integration into their local communities through a streamlined and coordinated resource development process.

Department of Developmental Services Strategic Plan 2003-2008, at 4, 6. Nonetheless, Lanterman fails to provide its residents with adequate, integrated, and meaningful day program and vocational opportunities.

Only a handful of Lanterman residents are engaged in competitive employment. At the time of our visit, there were only about a half dozen residents who worked at competitive jobs off-campus in the community. Apparently, no other Lanterman residents go off campus for competitive employment or even for day programming. Instead, just about all Lanterman residents are relegated to programming and other options in the segregated setting of the Lanterman campus. Dozens of Lanterman residents participate in an on-campus, sheltered vocational program called Community Industries where they get paid for completing various tasks such as shredding paper and sorting plastic utensils. There are a few other on-campus programs: the Main Street Residence is a segregated day program on campus that serves a small number of residents, and about 50 residents participate in on-campus senior programs with much less structure than traditional day programs. Unfortunately, the on-campus programs that appeared to offer the most meaningful activity were limited to very few residents. Only two dozen or so residents worked on campus in non-sheltered jobs and only another two dozen or so residents participated in activities at the on-campus equestrian center. Staff appeared to recognize the need for more integrated and meaningful day opportunities, yet seemed resigned that they could do little to effect change for Lanterman residents. On a positive note, the facility has developed and implemented a thoughtful on-campus program to help meet the needs of some residents who are non-ambulatory and have more involved and complex health care concerns.

7. Psychiatric Care

As part of the interdisciplinary approach to addressing residents' behavior problems, generally accepted practices require that State-operated facilities like Lanterman provide adequate psychiatric services for its residents with mental illness. Lanterman provides inadequate psychiatric care and services to its residents with mental illness, many of whom engage in harmful behaviors and/or are subjected to restraint. As we discuss in greater detail below, there are mental health staffing deficiencies at the facility; many of the residents with mental illness are not provided adequate mental health evaluations or treatment and follow-up in a timely manner; some residents receive psychotropic medication even though they do not have a mental illness diagnosis; and the facility has failed to

establish an adequate system for monitoring the side effects of psychotropic medications. Thus, Lanterman provides residents with deficient psychiatric care and treatment that departs substantially from generally accepted professional standards pursuant to Youngberg.

As of November 2004, Lanterman reported that 181 residents were diagnosed with a mental illness. The facility also reported that 226 residents received one or more psychotropic medications. This raises the concern that dozens of residents are being subjected to the administration of mind-altering medication even though they do not have a mental illness diagnosis. This represents a substantial departure from generally accepted practice.

We found evidence of insufficient availability of psychiatric services, significant delays in access to psychiatric services, and poor integration of psychiatric services with medical care and program services. These deficits place Lanterman residents at risk for inadequate treatment of psychiatric disorders, at risk for the continuation of related problematic behaviors such as aggression and self-injury, and at risk for continued exposure to increased side effects from psychotropic medication.

Even though about a third of Lanterman’s residents have a psychiatric disorder, the facility does not have a full-time psychiatrist on staff. Rather, it utilizes contractual psychiatric consultative services on a referral basis. Lanterman employs three contract psychiatric consultants to meet the needs of its residents with mental illness. However, only two of them see residents for treatment consultation; the third only serves on the facility’s behavior committee. One of the treating consultants is at Lanterman once per week and sees an average of only 10 residents per month. The second treating psychiatrist is at Lanterman once per month and sees an average of only three residents per month. This includes both follow-up visits as well as new consultations and assessments. As a result, residents with significant psychiatric symptoms and problematic behaviors rarely receive timely follow-up psychiatric consultation after an initial consultation. Moreover, facility staff schedule consult psychiatric services based on the availability of the consulting psychiatrist rather than based on the need of the residents with mental illness. Many Lanterman residents therefore continue to receive highly restrictive interventions and psychotropic medications without a psychiatrist’s oversight, input, or consultation.

The limited number of psychiatry hours at the facility has not proven sufficient to enable regular, ongoing evaluation and review of each Lanterman resident who receives psychotropic medication. From September 2003 to September 2004, only 127 of the 226 Lanterman residents who receive psychotropic medication were seen by the consulting psychiatrists; only 16 of the 226 were seen more than once for critical follow-up by the consultants. Thus, during this period, over 40 percent of the residents in need of a psychiatric consult were not seen within the year by a psychiatrist. This is unacceptable. Some residents have not seen a psychiatrist for a much longer period of time. For example, Lanterman documents reveal that 34 residents who take psychotropic medication (over 15 percent) had not seen a psychiatrist since at least 1999. This represents not just a failure of care, but an absence of care. In a gross departure from generally accepted standards of care, a handful of these residents had not seen a psychiatrist in about ten years, even though they continued to receive psychotropic medication. Once again, this is completely unacceptable.

Because the consult psychiatrists are at the facility for such short periods of time, there is limited interaction between them and each resident’s treatment team. This creates a host of problems. For example, the consult psychiatrists are not present at treatment team meetings when psychotropic drug changes are made. Psychiatric consultations that do not involve the team and/or the resident’s psychologist are of limited utility, especially since the consult psychiatrist will have had very little direct contact with the resident. Moreover, the consult psychiatrists do not review with the team the emergency use of psychotropic medications. Thus, they do not have any meaningful input with regard to the future course of treatment and intervention for residents who may be in ongoing crisis with untreated behaviors associated with aggression or self-injury.

Lanterman’s procedures used to assess and diagnose psychiatric disorders do not meet generally accepted professional standards. These deficits place certain Lanterman residents at risk for inadequate treatment of their mental illness. Adequate assessments are especially important in diagnosing mental illnesses in persons with developmental disabilities, because these individuals often cannot verbally describe their emotions and think as effectively as others. Consequently, a psychiatrist often makes presumptive diagnoses, and then prescribes interventions to assess if the diagnoses were appropriate. Without an ongoing re-evaluation of the diagnoses, the result is likely to lead to treatment not corresponding to the illness,

thereby resulting in untreated or mistreated psychiatric conditions.

In spite of the widespread availability of such procedures, in no case at Lanterman did we find that a formal psychiatric assessment procedure specifically for persons with mental retardation had been implemented. Moreover, for more than half of the Lanterman residents who have a psychiatric diagnosis, there is heavy reliance on historical, informal, and subjective information in conducting an assessment and formulating a treatment plan. This does not comport with generally accepted professional standards. Most importantly, this places the residents at risk for inappropriate diagnoses and treatment of psychiatric disorders, inappropriate medication, exposure to unnecessary side effects of medication, untreated behaviors, and injury.

The current procedures used in treatment planning and monitoring of medications substantially fail to meet generally accepted professional standards. In no case at Lanterman did we find evidence that a resident’s psychiatric symptoms were being measured independent of his or her behavior problems. Without this, it is unlikely that one can determine whether or not the psychiatric treatment – typically psychotropic medication – is or is not working to address the resident’s underlying mental illness. Improper or unsuccessful treatments thus may be continued indefinitely. We also found no evidence of documentation of short- and long-term strategies for addressing crisis and ongoing mental health concerns respectively. Without this, there is the danger that medications added temporarily to address an acute situation may be maintained for the long-term even though this is inappropriate and was not intended. Finally, there appears to be an over-reliance on medication solutions and insufficient emphasis on non-drug remedies, such as making modifications to behavior programs, changing environmental circumstances, and emphasizing skill acquisition. We found evidence at Lanterman that changes in non-drug treatments were attempted in only about 20 percent of the cases we reviewed where there were ongoing psychiatric concerns.

Finally, Lanterman fails to monitor, measure, and document the side effects of psychotropic medication accurately and consistently. In our sample, there was no documentation of the monitoring of side effects for about 90 percent of the residents we reviewed. The only documentation of side effects monitoring that we found related to the presence or absence of tardive

dyskinesia.[5] Even then, the facility failed to employ standard rating tools for the monitoring. We found that the consult psychiatrists did not monitor side effects and that the Lanterman physicians conducted only informal side effects monitoring. Monitoring side effects of psychotropic drugs is crucial, especially for persons with developmental disabilities because many may lack the ability to self-report. It is also critical because these medications can cause physically debilitating conditions. Failure to assess side effects properly poses many serious risks, including ineffective treatment and the exacerbation or creation of additional medical and/or behavioral problems. We note that Lanterman has become aware of this issue and appears to have begun development and implementation of remedial measures to better address side effects monitoring of psychotropic medications.

We found numerous situations at Lanterman that informed our findings discussed above. We set forth two illustrative examples here:

- N.Y. is a 61-year-old resident with a psychiatric diagnosis of Impulse Control Disorder. He has had a variety of psychiatric diagnoses over the years. He currently receives four psychotropic medications, and thus is subjected to polypharmacy (the prescription of multiple medications for the same condition). During 2003, he was restrained or secluded 97 times. During this time, he suffered a dozen significant injuries as a result of his aggression to others or to himself. In spite of this and many medication changes during this period, he was seen only once by a consult psychiatrist. There is no psychiatric plan in his record. An external report by the State's consultants revealed that N.Y. had several potential side effects from his medication that needed careful attention, but that there had been no ongoing tracking of his medication side effects. This resident has received psychiatric care that substantially departs from generally accepted professional standards pursuant to Youngberg.

- D.E. is a 51-year-old resident with a diagnosis of schizo-affective disorder bipolar type. He has a long history of severe aggression and self-injury. He receives four psychotropic medications, thus likely suggesting that he is

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[5] Tardive dyskinesia is a movement disorder. Symptoms of tardive dyskinesia include involuntary, aimless movements of the tongue, face, mouth, jaw, or other body parts.

subjected to polypharmacy. His behavior program permits 5-point restraint. From January to October 2004, he was restrained or secluded 862 times and received 128 doses of emergency psychotropic medication. He suffered 16 separate significant injuries during this period due to aggression and/or self-injury. During this period, Lanterman changed his psychotropic medication regimen on several occasions. Nonetheless, in spite of these ongoing and traumatic events, he was never seen by a consult psychiatrist during this period. This resident has also received psychiatric care that substantially departs from generally accepted professional standards pursuant to Youngberg.

C. HEALTH CARE SERVICES

Lanterman fails to provide residents with adequate medical care. Youngberg v. Romeo, 457 U.S. at 315, 323, 324. General medical care and nursing services are deficient, both in their direct provision and their oversight. We uncovered preventable illnesses, preventable hospitalizations, and preventable deaths among Lanterman residents. We discuss a few illustrative and disturbing examples immediately below. In addition, Lanterman neither provides adequate nutritional and physical management nor adequate occupational and physical therapy, placing its residents at great risk for injury or death.

1. Medical Care and Nursing Services

The medical care and nursing services provided at Lanterman substantially depart from generally accepted professional standards and do not comply with federal regulations. In particular, Lanterman fails to: (a) provide adequate medical and nursing assessment and treatment; (b) provide effective medical direction; and (c) ensure that practitioners are documenting appropriately.

a. Medical and Nursing Assessment and Treatment

Medical and nursing assessment and treatment at Lanterman are grossly deficient. Practitioners fail to screen and monitor medications for appropriateness and efficacy. They also fail to initiate proactive treatment planning for residents based on their individualized needs. The risk of harm from these failures is not hypothetical. The following examples are illustrative:

- Lanterman failed to promptly treat Q.M., a 34-year-old resident with a well-known history of bowel obstruction, after he began vomiting and slumped to the floor. The

physician on duty did not examine Q.M. but instructed staff over the phone to "[c]lean him up and put him back to bed, keep an eye on him and put him up for Doctor's attention in the a.m." Mr. M. was not seen by a physician until 15 hours after his first episode of vomiting, at which time the doctor suggested that obstruction might be the cause and ordered that Q.M. be sent to the emergency room. An hour and 15 minutes later and still at Lanterman, Q.M. had a grand mal seizure and his blood pressure dropped. The physician was notified but did not return to see the resident. Q.M. was not transferred to the hospital until over two hours after the physician wrote the transfer order. Upon arrival at the hospital, his abdomen was "extremely hard, rigid and tender" and he had no bowel sounds. Less than seven hours later, Q.M. died. The autopsy report determined the cause of death to be "Small Bowel Obstruction with Ischemia" (lack of blood supply). Lanterman was fined $25,000 for this failure of care by the California Department of Health Services, the highest allowable fine under California law for this type of State facility.

- K.E. was sick for four days with symptoms of fever, increased heart rate and respiratory rate, and decreased blood oxygen saturation (indicative of ineffective oxygenation and resulting in a lack of oxygen being carried to the cells). For three days, Lanterman medical professionals did not attend to K.E., despite being aware of her shallow, labored breathing. K.E. was admitted to the hospital on the fourth day and was diagnosed with pneumonia. For the four days leading up to her hospitalization, K.E. received no serious medical attention in response to her worsening pulmonary status. Proper treatment could have prevented the progression of her illness and her ultimate hospitalization.

- K.E. has a seizure disorder and experienced a prolonged seizure due to low levels of anticonvulsant medication in her blood. Yet her annual assessment reflected no analysis of what caused her to have the low drug levels and no treatment plan to prevent future seizures. The assessment also contained no medical plan to prevent fractures, recurrent aspiration, or pneumonia, all conditions to which she is predisposed due to her seizure disorder.

- K.E. also has a history of multiple decubitus ulcers (bed sores). At the time of our review, her skin had not been monitored in almost six months. Professional standards require weekly monitoring for someone, like K.E., with a

history of bed sores. Practitioners had not provided any analysis of why she has had recurrent skin breakdown nor had they implemented a plan to prevent it. Appropriate care planning could have resulted in her developing fewer decubiti, which cause pain and mobility issues and can lead to blood infection and death.

- T.W. has a history of multiple decubitus ulcers as well. In May 2003, his Individualized Program Plan noted that he had had five pressures sores, four on the left hip and one on the right heel, during the course of the previous year. Sometime later, T.W. developed a pressure ulcer on his right fifth toe, and in November 2003, the toe and the supporting bone in the foot were amputated.

- O.V. has osteoporosis and a seizure disorder. Lanterman doctors suspected that O.V.'s actual seizure activity was much more frequent than reported. However, no medical or nursing plan was devised to improve seizure reporting for this resident. In May 2004, Lanterman found that O.V.'s anti-seizure medication was below therapeutic levels but, at the time of our review five months later, they had not tested his serum levels. A low blood level of anti-seizure medication can lead to an increase in seizure activity.

- Although F.P. has a suspected allergy to a class of medications called benzodiazepenes, he is prescribed Ativan, a benzodiazepene, administered three times a day. This could result in a potentially-fatal allergic reaction.

Oversight of nursing services at Lanterman is likewise inadequate to provide sufficient guidance, technical assistance, and training to its nurses. For instance:

- The acute care facility at Lanterman contains a sedation clinic. The nurses working in the clinic administer conscious sedation to residents scheduled for dental procedures. None of the three nurses assigned to the clinic, however, have been tested to ensure that they know how to administer conscious sedation.

- A nurse in the acute care facility administered water and medication through a gastric tube without first verifying proper placement of the tube. The head of the bed was at less than 30 degrees, too low to guard against reflux of stomach contents into the esophagus. When the medication was administered, the resident began coughing and required suctioning of excessive secretions.

In addition, nurses are supervised by non-clinicians, which results in poor quality of care and inadequate nursing assessments and treatment plans. This might explain, in part, why during fiscal year 2003-2004, there were 5,245 medication errors at Lanterman. A number of errors placed residents at significant risk. For example, there were

- 1,690 incidents of administering medications without orders from physicians;
- 1,265 incidents of failing to provide a prescribed medication;
- 130 incidents of administering the incorrect dosage of a medication;
- 86 incidents of providing the wrong medication or treatment;
- 38 incidents of not starting a new order;
- 26 incidents of seizures not being recorded;
- 17 incidents of medications not being held as per a physician's order; and
- three incidents of discrepancies in the controlled medication count.

Moreover, many of the nursing evaluations we reviewed were inconsistent with the resident's ongoing problems. For example, a nursing assessment for F.P. recommended deleting the risk of seizures from his risk assessment, despite the fact that he was on three anticonvulsant medications, used a helmet to protect his head from falls during seizures, and had had a recent fracture due to a fall during a seizure.

Lanterman residents are often assigned a "do not resuscitate" or "DNR" status. Generally accepted professional standards dictate that the presence of a disability alone is not an adequate clinical indication for a DNR order. In fact, Lanterman policy articulates this.[6] In contravention of both

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[6] Lanterman Developmental Center Administrative Directive 261: Life Sustaining Procedures/Do Not Resuscitate Orders, Mar. 28, 2003, at 1 ("The presence of a developmental disability is not, by itself, a clinical indication for a [Do Not Resuscitate]

standards and policy, Lanterman assigns DNR orders based solely on the presence of a disability. For example, O.V., a 15-year-old youth at the time of our review, does not have any untreatable medical conditions yet he has a DNR order "due to irreversible brain damage." His chart reflects that the DNR was applied due to his mental retardation. Even though there is no indication that O.V.'s conservator agreed with this order, O.V.'s DNR order was approved by the Lanterman bioethics committee.

b. Medical Direction

Institutions for individuals with developmental disabilities are required to have a medical director.[7] The medical director shares responsibility with other members of the administration for the overall medical care of the residents.[8] The quality of the medical direction at Lanterman substantially departs from generally accepted professional standards. Lanterman's medical director is a general practitioner who provides limited oversight of staff and consultative physicians and of the overall health care policies and procedures at the facility. No physician oversees nurse anesthetists in their administration of anesthesia. Physician peer review is infrequent. Under the medical director's oversight, mortality reviews consist only of a limited review of the causes of death and practically no discussion of how care could have been improved.

Many of the administrative directives at Lanterman have not been revised in years, and there are few medical care guidelines in place. For example, the facility's infection control policies and procedures do not contain provisions addressing such crucial areas as identification and tracking of hospital-acquired infections and diseases, antibiotic-resistant infection prevention, and prevention of device-related infections, such as those associated with intravascular devices, ventilators, indwelling catheters, tube feedings, tracheostomies, and surgical sites. In one cottage in September 2004, several residents developed "boil-like lesions" which were to be tested for an antibiotic resistant infection. There was no evidence that the infection control committee ever followed up on this.

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order or an order to withhold life-sustaining treatment.).

[7] 42 C.F.R. § 483.75(i)(1).

[8] See 42 C.F.R. § 483.75(i)(2)(ii).

The medical director is also responsible for making certain that staff are adequately trained and that they are prepared in the event of a medical emergency. Lanterman provides inadequate medical education to the medical staff. For example, nursing staff are not educated on seizure management, fractures, or decubitus ulcer treatment and prevention -- issues frequently encountered at Lanterman. Generally accepted professional standards require a facility such as Lanterman to conduct adequate and frequent mock codes or drills to ensure staff training and preparedness. Lanterman's medical director told us that he was not sure whether the facility conducts mock codes at all and, if so, how and when they are reviewed. In fact, Lanterman conducts mock codes infrequently and when they are conducted they do not include all necessary staff. More importantly, the mock codes themselves are inadequate to properly prepare staff for such emergencies. For example, we discovered that there was no wrench available to open the oxygen tank on one code cart. The code blue committee reviews actual codes too infrequently and it inadequately tracks and monitors problems once they have been identified. In order to ensure the provision of adequate supports and services for Lanterman's residents, all these concerns should have been noted and addressed by the medical director in a timely fashion.

c. Physician Documentation

Generally accepted professional standards require that clinical records be complete, accurate, organized in a manner that allows relevant information to be identified and utilized in medical treatment decisions, and sufficiently detailed to provide for continuity of care. We noted inadequacies in documentation throughout Lanterman's medical records. The facility's medical records are poorly organized and lack a problem list in the front of the chart. A readily-located problem list is essential to help a consultant or on-call physician easily identify a resident's medical and surgical history when an evaluation is being conducted. In addition, seizure charting is inadequate. This lack of proper documentation prevents clinicians from adequately assessing and managing residents with seizure disorders. Health maintenance testing on Lanterman residents, such as mammograms, colonoscopies, and cholesterol screening, is not tracked adequately and charted, making it difficult to follow whether residents are receiving adequate and timely preventative health care.

Documentation was often missing from charts altogether. The following examples are illustrative:

- O.V. has been diagnosed with a hearing impairment, glaucoma (an eye disease characterized by partial to complete loss of vision), a hiatal hernia (a condition where part of the stomach protrudes through the esophageal opening of the diaphragm), and scoliosis (curvature of the spine). None of these conditions appeared on his problem list.

- J.S. has a seizure disorder and was recommended for a neurological follow-up in three months. While a note by his primary care physician indicates that he was seen by the neurologist, the chart does not contain the consultation.

- K.E. has an allergy to intravenous dye and a seizure disorder. Neither is noted on the front of her chart, as is standard practice. She was admitted to the hospital in March 2004 and July 2004 but the discharge summaries from these hospitalizations are not in the chart.

2. Nutritional and Physical Management

Lanterman's nutritional and physical management services pose serious risks to residents. Specifically, Lanterman fails to adequately assess individuals with nutritional and physical management concerns. In addition, the facility fails to provide appropriate seating systems, alternate positioning options, and adequate assistance, positioning, and monitoring during mealtimes. Finally, Lanterman staff do not demonstrate adequate knowledge and skills in providing physical assistance, supports, and alignment for residents and fail to provide the necessary monitoring to ensure ongoing safety and effectiveness. As a result, Lanterman residents are subjected to a range of serious and, in some cases, fatal conditions.

a. Inadequate Assessment of Nutritional and Physical Needs

Generally accepted professional standards dictate that facilities like Lanterman provide comprehensive assessments of each resident's individual nutritional and physical needs. The facility lacks any effective approach to addressing the health and medical issues of its residents from a nutritional and physical support standpoint. Each year since 1998, there have been between nine and 19 airway obstructions requiring abdominal thrusts. In 2004 alone, two residents died due to complications from choking incidents. In spite of this, Lanterman's dysphagia

team only conducted evaluations for four residents over the past three years.[9]

In addition, Lanterman is home to numerous individuals with multiple health risk indicators such as gastroesophageal reflux (regurgitation of stomach contents into the esophagus), dysphagia (difficulty swallowing), gastrostomy or ileostomy tubes (surgically-inserted feeding tubes), and tracheostomies (surgical openings in the trachea which facilitates breathing) who would benefit from a team review process. While residents with these risk factors appear to have been identified by the facility, except in the case of fractures, Lanterman lacks any system for routine interdisciplinary team assessment to identify, support, and monitor individuals at the highest risk for physical/nutritional management problems. For example:

- Among other conditions, P.R. has diabetes, weight loss, gastrointestinal bleeding, a gastrostomy tube, and a tracheostomy. He has suffered from numerous bouts of pneumonia and aspiration pneumonia (lung disease caused by the sucking of fluid or a foreign body into the airway when drawing breath). His physical therapy services, however, have been discontinued since September 2000, even though his therapy goals remain unmet. This high-risk resident has received health care that substantially departs from generally accepted professional standards pursuant to Youngberg.

- K.N. is considered at great risk for aspiration. He has severe swallowing problems and has experienced recurrent episodes of pneumonia. Between November 2002 and March 2004, two swallow studies and a mealtime assessment recommended that K.N. have a feeding tube inserted. At the time of our visit in October 2004, K.N. was still being fed by mouth. There was no evidence that a comprehensive team assessment had ever been done for K.N. This high-risk resident has also received health care that substantially departs from generally accepted professional standards pursuant to Youngberg.

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[9] A dysphagia team is an interdisciplinary group that intervenes to ensure individuals' safe and efficient ingestion and positioning at mealtimes.

b. Inadequate Seating Systems and Alternate Positioning Options

Lanterman also fails to assess, implement, and monitor for the provision of adequate seating systems and alternate positioning options for its residents. Generally accepted professional standards require that residents be provided with adequate support and alignment at mealtimes to minimize health risks such as aspiration, gastroesophageal reflux (the backward flow of stomach contents into the esophagus), and musculoskeletal deformity. In addition, such postural supports are necessary to optimize functional skill abilities at mealtime.

We observed numerous residents in seating systems which did not provide the requisite support and alignment. Residents were seated in poor alignment at mealtimes as well as at other times throughout the day. Among other problems, residents were leaning to the side, collapsing forward, hyperextending their heads backward, tilting their pelvises posteriorly, excessively extending their legs on elevated leg rests, and deprived of adequate foot support.

In addition, Lanterman, in contrast to generally accepted practices, has no system to ensure that appropriate, comprehensive seating and alternate positioning assessments are completed and that these devices are provided to residents. We did not find a single comprehensive seating assessment in the course of our review. Lanterman residents are not provided adequate alternate positioning options for pressure relief and other therapeutic benefits. Devices that facilitate proper alignment, support the trunk and extremities, and promote elongation, improving ventilation, digestion, and elimination, are not made available to Lanterman residents. Repeatedly, we observed residents with decubitus ulcers and residents at risk for gastroesophageal reflux either lying flat or lying at less than a 45 degree angle in bed, placing them at greater risk for skin breakdown and aspiration.

Moreover, Lanterman lacks an effective system to monitor the condition and appropriateness of its residents' seating systems. Lanterman does not properly identify concerns regarding alignment and support impacting on residents' health and safety, particularly where mealtimes are concerned. For example, Lanterman's existing monitoring system reported that only five percent of individuals reviewed were "not in the correct position." In stark contrast, we noted concerns regarding positioning for over half of the 80 residents we observed seated in wheelchairs.

c. Inadequate Transfers

A significant number of Lanterman residents have limited mobility and, therefore, depend on staff to transfer them from one position or location to another. When transfers are conducted improperly, residents are at a significant risk of harm, including nerve damage, fractures, and various injuries resulting from falls. Transfers at Lanterman substantially depart from generally accepted professional standards. The facility fails to provide competency-based training in transferring and lifting procedures, instead giving this instruction on videotape. Indeed, staff are only trained on transfers after an accident or injury occurs. We observed numerous unsafe transfers. For example:

- A.M. has a gastrostomy tube and a tracheostomy. He was transferred from his bed to a wheelchair in a very flat position, and his head was not adequately supported. This predisposed him to aspiration and displacement of the tracheostomy tube.

- Professional staff lifted D.W. up by her pants to reposition her during a physical medicine and rehabilitation clinic. This demonstrated a lack of proper knowledge and skills in repositioning a resident.

- One staff member was apparently intending to transfer O.C. from his bed to a wheelchair without assistance. When she became aware that she would be observed, the staff member obtained the assistance of another person. The transfer was awkward and unsafe. The resident’s leg was struck by a metal bar during transfer and, once he was in his wheelchair, staff used his legs to pull him out of the room, placing him at risk for injury and/or fracture.

The facility has identified fractures, in particular those of unknown origin, as a significant concern. Nearly half of the residents who suffered fractures in 2004 are seated in wheelchairs and therefore likely require staff assistance to transfer between their wheelchairs and their beds. This correlation suggests that attention to the performance of transfers should be carefully evaluated facility-wide.

d. Inadequate Mealtime Supports

Lanterman has some strengths in the area of mealtime supports. Generally, we found mealtimes at Lanterman to be

organized. We also noted that staff typically attempt to promote residents' independence.

However, Lanterman does not provide adequate mealtime supports in contravention of generally accepted professional standards. Generally accepted professional standards require residents to be protected from injury while ingesting fluid or nutrition. If food and fluid are introduced by staff too quickly or are presented in quantities that are too large, the person being assisted may not be able to safely swallow, clear, and take a breath before the next portion is offered. This places residents at risk for aspiration and choking. Lanterman staff frequently permit food to be ingested or present food to residents at too fast a pace. In some cases, we observed residents' meals to be completed in approximately five minutes. Some residents were also presented with or permitted to take bites or sips that were too large. By way of example, we observed the following during our tour:

- L.H. has had at least five choking incidents since 1997 and has a specially-ordered diet due to her swallowing difficulties. Despite the fact that her assessment indicated that she should have close supervision with all oral intake and that an earlier swallow study revealed a delayed swallow and silent aspiration, during our observation she did not receive an adequate level of oversight while eating. We saw her taking large bites and we observed her to be coughing and throat-clearing during her meal. Staff appropriately cued her to slow down, but then later, unsupervised, she stuffed entire quarters of toast into her mouth and swallowed them whole without sufficiently chewing them. Because of the lack of staff oversight during her meal, L.H. was at risk for choking and aspiration.

- Staff repeatedly furnished E.G. with water while her head was hyperextended backward and, at times, turned to the side. We observed her coughing at least seven times during this period. This method of providing her with liquids placed her at risk for aspiration.

- A number of times throughout her meal, R.F. was offered bites of food while she was talking. Some of the bites were too large. She coughed throughout the meal. The staff member's method of feeding this resident placed her at risk for aspiration.

Moreover, staff frequently fail to facilitate appropriate postural alignment while residents are ingesting food or fluids or receiving enteral (given by way of the intestine, typically through a gastrostomy tube) nutrition, placing residents at risk for choking, aspiration, and gastroesophageal reflux. In some cases, staff actually contribute to residents' poor alignment. Numerous staff were observed to stand above eye level range while providing assistance, encouraging residents to hyperextend their necks to look up at them.

Furthermore, Lanterman does not provide residents with mealtime plans designed to prevent them from aspirating or choking and promote mealtime skill acquisition. Assessments are initiated by physician referrals and are reactive rather than proactive in nature. There are no written mealtime plans to provide clear instructions for direct care staff on things like mealtime precautions, positioning, and adaptive equipment. Decisions about residents' supports are often made based upon protocol and not the resident's individualized needs for intervention and follow-up. For example:

- C.J. experienced a choking incident requiring the Heimlich maneuver while eating a burrito, her third such episode in six years. There was no evidence of any follow-up assessment after her most recent choking incident even though her mealtime program was clearly inadequate to prevent choking. Inexplicably, Lanterman protocol did not require follow-up because the incident involved food that was not permitted by C.J.'s diet order. Adherence to such a protocol placed the resident in danger of a recurring choking episode and possible aspiration.

- M.V. was referred for an assessment by an occupational therapist due to having had two choking incidents within one week, one of which required the Heimlich maneuver. The therapist recommended close supervision, appropriate food items, and for the therapist to be notified if M.V. experiences any other choking or near-choking incidents. No follow-up was recommended and, as of the time of our tour over three years later, there had been no assessment completed on this resident since. Professional staff are awaiting another choking incident before providing further supports. In view of the fact that two choking deaths occurred during the year prior to our tour, this approach places M.V., and others like him, at great risk for future choking episodes and even death.

- L.H. was noted to cough before, during, and after swallowing and to overstuff her mouth during meals. She choked three times between February 2002 and June 2004. The second incident involved a large bead rather than food. Because this incident involved her choking on something other than food in her prescribed diet, it was erroneously deemed not to meet the facility's criteria for identifying the resident as a choking risk. After the third choking incident, an assessment merely recommended follow-up in one year, the exact approach utilized after the prior two choking incidents, which had been ineffective in preventing her from choking yet again. This recommendation was insufficient to protect L.H. from risk of harm from future choking episodes.

The facility also fails to effectively monitor the provision of mealtime assistance to ensure that it is safe and effective, particularly for those identified to be most at risk. Lanterman has no clear, systematic, and routine method in place to monitor mealtimes, track each person's progress, or validate staff compliance with implementation. There was no evidence that individuals receiving enteral nutrition were monitored either. During our visit, we observed numerous instances of staff using unsafe practices at mealtimes. These concerns appeared to go unnoticed by professional staff at Lanterman.

For instance, we observed that a therapist was conducting a mealtime assessment of J.T. J.T. was taking huge bites and, while staff were consistently cuing her to slow down, they did not direct her to take smaller bites. More importantly, the therapist did not instruct staff accordingly. J.T. coughed two to three times after finishing her meal. The way she was eating her meal placed J.T. at risk for choking and aspiration, but neither professional nor direct care staff noted this or acted to rectify it.

3. Inadequate Therapy Services

Lanterman fails to provide adequate and appropriate physical and occupational therapy services. As a result, residents face an increased risk of contractures and deformity, resulting in loss of independence and functional skills. Generally accepted standards of practice require developmental centers like Lanterman to conduct a comprehensive evaluation of each resident upon admission and, for individuals who receive therapy supports, at least every three years thereafter, to provide a foundation against which to measure changes. Therapists may then assist the residents in establishing individualized goals.

In addition, residents who would benefit from an enhanced communication system must have access to such a system to optimize each communicative effort. Lanterman fails to enhance or promote functional independence and skill acquisition in the area of communication services. We noted that communication supports for people who needed them were sorely lacking at Lanterman. A single speech language pathologist visits the facility approximately twice a week to service all 580 residents. Outside of their annual Individual Program Plan assessments, we did not see a single resident receiving communication supports during our tour. This was true despite the fact that we met numerous individuals who would benefit from such supports. This represents a gross departure from generally accepted standards for those residents who need such communication supports.

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

We also harbor certain reservations at the ways in which the State carries out its legal obligation to serve institutionalized Lanterman residents in the most integrated setting appropriate to their individualized needs.

1. Legal Framework

The regulations promulgated pursuant to the Americans with Disabilities Act ("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.

Further, with the New Freedom Initiative, President George W. Bush announced that it was a high priority for his Administration to tear down barriers to equality and to expand opportunities available to Americans living with disabilities. As one step in implementing the New Freedom Initiative, on June 18, 2001, the President signed Executive Order No. 13217, entitled "Community-Based Alternatives for Individuals with Disabilities." Specifically, the President emphasized that unjustified isolation or segregation of qualified individuals with disabilities in institutions is a form of prohibited discrimination, that the United States is committed to community-based alternatives for individuals with disabilities, and that the United States seeks to ensure that America's community-based programs effectively foster independence and participation in the community for Americans with disabilities. Exec. Order No. 13217, §§ 1(a)-(c), 66 Fed. Reg. 33155 (June 18, 2001). The President directed the Attorney General to "fully enforce" Title II of the ADA, especially for the victims of unjustified institutionalization. Id. at § 2(c). As set forth below, the State is failing to comply with the ADA with regard to placing persons now living in Lanterman in the most integrated setting appropriate to their individualized needs.[10]

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[10] We note that the Ninth Circuit's recent decision in Sanchez v. Johnson, 416 F.3d 1051 (9th Cir. 2005), regarding payments to community-based providers, is not controlling authority with regard to this CRIPA matter. Specifically, in Sanchez, the Ninth Circuit affirmed that a class of California plaintiffs with developmental disabilities lacked standing to assert claims under the Medicaid statute pursuant to 42 U.S.C. § 1983, and upheld the denial of plaintiffs' request for an injunction compelling California state officials to increase payments to community-based service providers. In its ruling, the court held that the requested relief would require a "fundamental alteration" of the State's plan for de-institutionalization. While the court set forth broad, positive conclusions about the State's integration efforts regarding the needs of persons with developmental disabilities in the State's vast system, the Sanchez decision is distinguishable on a number of grounds from our present CRIPA investigation. For example, there is no issue here with regard to our standing or our right to pursue independent Medicaid remedies. Moreover, the United States here is not suggesting as a minimal remedial measure the state-wide increase of payments to community providers. In

2. Recent Community Placement Numbers

The number of people being discharged from Lanterman to integrated community placements has been decreasing in recent years. From 1995-1999 respectively, Lanterman discharged 77, 75, 45, 35 and 26 residents to the community. The numbers have continued to fall each year since then. Only 19 were transferred in 2000, 12 in 2001, 7 in 2002, and 7 in 2003. Indeed, more Lanterman residents have died in recent years than have transitioned to the community. The declining number of placements is troublesome because not all Lanterman residents are difficult to place. While it may be true that some of those who live at Lanterman may have unique care considerations and face more barriers to placement than others, this does not mean that they cannot be placed with appropriate protections, services, and supports, and it does not fully explain the significant recent decline in the pace of placements from the facility.

3. Fiscal Considerations

The slowed pace of placements from Lanterman may be due partly to fiscal limitations. For example, the State's FY 2004-2005 Community Placement Plan Summary provides for a budgeted total of only 232 community transitions from *all* seven of the State-operated developmental centers. About a quarter of these 232 slots have already been designated for Agnews residents given the impending closure of that facility. Thus, there are very few budgeted slots for Lanterman residents this year.[11] The same problematic situation recurs from fiscal year to fiscal year.

In the mid-1960s, California began to establish a network of "regional centers" throughout the State to facilitate the

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addition, the Sanchez court did not consider pertinent findings contained within this letter. For example, in reaching its conclusions about the State's overall integration efforts, it does not appear that the court considered that: personnel from the regional centers (discussed below) often do not attend individual Lanterman resident IPP meetings which may facilitate placement decisions and plans; teams fail to conduct and memorialize adequate team discussions with regard to the most integrated setting for individual Lanterman residents; and community opportunities or slots available to Lanterman residents are limited.

[11] It is notable that the estimated average annual cost to serve a resident at Lanterman was $215,702.95 for FY 2004-2005.

transition of institutionalized persons with developmental disabilities into integrated community placements. Currently, there are 21 regional centers. In essence, the regional centers control access to community homes, community programs, and other critical community resources. Institutionalized residents, like those at Lanterman, may not transition to integrated settings easily without the cooperation and active assistance of their respective regional centers. Each qualified resident of a State developmental center is a client of one of the State's 21 regional centers. At Lanterman, several different regional centers serve clients who live at the facility.

Each regional center is a private, non-profit corporation with a board of directors. Nonetheless, each is closely tied to, and dependent upon, the State for its ongoing operations. For example, each regional center has an annual contract with the State through the State's Department of Developmental Services ("DDS"). We understand that the State is free to terminate this contract and contract with a new non-profit corporation at its discretion. The State constantly monitors and oversees its regional center contractors and can impose financial disincentives for poor performance. DDS may conduct audits of the operations of its regional center contractors. Perhaps most significantly, each regional center is dependent on DDS to request and obtain its annual operating funding from the State legislature.

The San Gabriel/Pomona Regional Center ("SGPRC") is the closest regional center to Lanterman and has the largest number of clients living at Lanterman compared to any other regional center. At the time of our visit, SGPRC served 95 clients at Lanterman. For FY 2004-2005, SGPRC was given five out of the 232 community slots. As we discuss below, without allocated funding, the other 90 SGPRC clients at Lanterman are not likely even to be considered for community placement during this fiscal year. Similar limits exist at Lanterman for clients of all of the other regional centers.

4. Impact on Team Decisions Pursuant to *Olmstead*

In spite of the limited number of budgeted community slots for this year, SGPRC personnel informed us that generally, regional center placement activities are driven by Lanterman team decisions as to who is appropriate for community placement. In short, if a Lanterman team determines that a person should be placed and the affected individual does not oppose placement, the SGPRC claimed that the regional center would act on the team

recommendation to help effect placement. This Olmstead-oriented, bottom-up approach is how the process should work.

In spite of this, however, facility personnel informed us that the Lanterman teams, in effect, do not even recommend residents for placement in the community until after the regional center tells the facility that a community slot has opened. Thus, there is a legitimate concern that top-down constraints based on capacity limits may tend to overwhelm person-centered, needs-based, bottom-up considerations. Indeed, the regional center acknowledged that it only conducts a more in-depth, "whole person assessment" for a Lanterman resident when a community site has already been identified for that person.

5. Individual Program Plan Process

Lanterman's Individual Program Plan ("IPP") process generally is inadequate with regard to addressing residents' needs for placement in the most integrated setting. As we discuss below, this is primarily due to the fact that: (1) critical regional center personnel often do not attend annual IPP reviews, thus thwarting any meaningful discussion of community alternatives; and (2) the team fails to make and memorialize a considered team determination on proper placement and whether or not the person opposes such placement.

Regional centers are supposed to play a pivotal role in the development and annual review of each Lanterman resident's comprehensive care plan, or "IPP."[12] The IPPs are designed to address care and services to be provided at the facility and are also to cover issues related to placement in the most integrated setting.[13] Nonetheless, in spite of the fact that regional center personnel are to attend the residents' annual team

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[12] See State Guidelines for Regional Center, Community Placement Plan, Nov. 2003, at 5 ("Regional centers ... are responsible for coordination of efforts in assessment, development of IPPs, planning, transition and deflection for the benefit of consumers").

[13] See Lanterman Administrative Directive 215: Community Referral and Placement ("Planning for movement to a more natural living arrangement is an integral part of a client's Individual Program Plan").

meetings,[14] they often do not. In fact, Lanterman documents reveal that regional center personnel attended only about 60 percent of the annual team meetings for residents from September 2003 to September 2004. Given that the regional centers largely control access to critical community resources for institutionalized residents, the absence of regional center personnel at the annual team meetings is especially problematic with regard to initial and ongoing placement determinations, as well as with regard to the possible development and implementation of more integrated community alternatives for Lanterman residents.

Lanterman's own policy requires that the "Individual Program Plan shall include provision of services and training designed to reduce or eliminate barriers to living in a more natural setting and shall identify the specific supports needed to enable the individual to successfully meet his or her goals." Lanterman Administrative Directive 215: Community Referral and Placement. The policy further specifies that "Opposition to placement [] will be documented ... [the] Interdisciplinary Team [shall] [f]ormulate a plan directed toward living successfully in a less restrictive environment ... [a]t least annually, review the [IPP] and the client's progress to determine if the individual should be recommended for community living arrangements ... [and] [r]ecommend community placement as appropriate"). Id.

In spite of this and related Olmstead requirements, Lanterman IPP documents typically do not even contain a memorialization of a full team discussion of what is the most integrated setting for the person. If a Lanterman resident is not already in the active transition process to an identified community site, the team typically will set forth a short, conclusory statement such as that the resident is considered "appropriately placed" within Lanterman and that there are "no plans" for placement at this time. Normally, there is no further discussion or explanation of the team's rationale. We were never provided with a satisfactory explanation as to why the more comprehensive and in-depth community assessment is only given for residents with identified community sites. Moreover, in this situation, there is at best only a cursory listing of the supports and services the person may need in the community.

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[14] See Lanterman Administrative Directive 215: Community Referral and Placement ("Placement planning involves the ID Team, including the person served, *a representative of the appropriate Regional Center* and the family, guardian, conservator or personal advocate") (emphasis added).

Finally, there is typically no memorialization of whether or not the person (or his or her legal decision-maker) opposes placement and whether or not this has been an informed decision. Not only does all this violate the facility's own policy, it thwarts the spirit and letter of the Olmstead opinion.

6. Positive Aspects

Amidst these serious concerns, we found some positive developments in this area. For example, the regional centers appear to be successful in helping to prevent the admission of residents to State institutions like Lanterman in the first place. Moreover, the regional centers appear to engage in a thoughtful and considered approach to try to meet the individualized needs of the few clients identified for community placement each year. This includes person-centered, interdisciplinary team transition meetings at Lanterman that are focused on the individualized needs of each resident. The regional centers bring their resources and expertise to help find appropriate homes and expand community capacity when needed. Once a prospective home is identified, the regional center facilitates the resident making one or several onsite visits of the home in order to ensure a proper fit. Finally, in conjunction with the regional center, the Lanterman Regional Project also appears to provide helpful support services to persons who are now living in the community to help ensure that these placements continue to meet the needs of these persons. These efforts are laudable. In the final analysis, however, significant concerns remain given how few Lanterman residents may be impacted by these positive initiatives in any given year.

III. MINIMAL REMEDIAL MEASURES

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

A. Protection from Harm and Reasonable Safety

1. Ensure that residents are supervised adequately by trained staff and and that residents are 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 timely and complete 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, especially fractures, lacerations, and injuries of unknown origin, so as to develop and implement remedial measures that will help prevent future events. Include systemic recommendations in investigation reports and ensure the prompt implementation of remedial measures to prevent future occurrence of incidents and injuries.

B. Training, Habilitation, Behavioral Services, Restraints, and Psychiatric Services

1. Provide residents with adequate training, including behavioral and habilitative services, needed to meet the residents' ongoing needs. These services shall be developed by qualified professionals consistent with accepted professional standards to reduce or eliminate risks to personal safety, to reduce or eliminate unreasonable use of bodily restraints, to prevent regression, and to facilitate the growth, development, and independence of every resident. To this end, the facility shall take the following steps:

(A) Ensure that all residents receive meaningful habilitation daily. Ensure that there is a comprehensive, interdisciplinary habilitative plan for each resident for the provision of such training, services and supports, formulated by a qualified interdisciplinary team which identifies individuals' needs, preferences and interests. Ensure that the plans address the residents' needs, preferences and interests in an integrated fashion. Ensure that staff are trained in how to implement the written plans and that the plans are implemented properly.

(B) Provide an assessment of all residents and develop and implement plans based on these assessments to ensure that residents are receiving vocational and/or day programming services in the most

integrated setting to meet their needs. Ensure that there is sufficient staffing and transportation to enable residents to work off-campus or attend off-campus programming when necessary.

(C) Provide residents who have 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 resident's behavior.

(D) Develop and implement an adequate array of comprehensive, individualized behavior programs for the residents who need them. Through competency-based training, train the appropriate staff how to implement the behavior programs and ensure that they are implemented consistently and effectively. Record appropriate behavioral data and notes with regard to the resident's progress on the programs.

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

2. Ensure that highly restrictive interventions or 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) Develop and implement a protocol that places appropriate limits on the use of all restraints, especially the use of two-point, four-point, and five-point restraints, as well as the routine use of emergency chemical and unplanned physical or mechanical restraints. Ensure that only the least restrictive restraint techniques necessary are utilized, and, that restraint use is minimized.

(B) Ensure that ineffective behavior programs that may contribute to the use of restraints are modified or replaced in a timely manner. For those individuals subjected to chronic use of restraint

associated with difficult behavior problems, 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) Document and track fully the use of personal control and seek to reduce its use significantly.

3. Provide adequate psychiatric services consistent with accepted professional standards to residents who need such services. To this end, the facility shall take these steps:

(A) Procure adequate psychiatry hours to meet the needs of the residents.

(B) Ensure that each resident with mental illness is provided with a comprehensive psychiatric assessment, a 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. Ensure that the psychiatrist(s) provide new assessments and/or revisions to any aspect of the treatment regimen whenever appropriate. Ensure that psychiatric services are developed and implemented in close collaboration with the facility's psychologists to provide coordinated behavioral care.

(C) Ensure that psychotropic medication is only used in accordance with accepted professional standards and that it is not 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. Ensure that no resident receives psychotropic medication without an accompanying behavior program.

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

C. Clinical Services

1. Provide adequate medical care and nursing services consistent with accepted professional standards to residents who need such services. To this end, the facility shall take these steps:

   (A) Ensure that all primary care and consulting providers screen and monitor medications for appropriateness and efficacy.

   (B) Provide each resident with proactive treatment planning based on his or her individualized needs.

   (C) Ensure that oversight of nursing services is provided by experienced, trained nurses.

   (D) Provide all nurses with training in assessment and treatment planning for individuals with developmental disabilities.

   (E) Ensure that no resident is assigned a Do Not Resuscitate designation based solely on the presence of a disability.

   (F) Ensure that an appropriately qualified medical director provides adequate oversight of Lanterman's staff physicians as well as facility policies and procedures.

   (G) Implement a regular, formalized physician peer review system in accordance with generally accepted professional standards.

   (H) Implement a regular, formalized mortality review system, including an appropriate follow-up in the mortality review committee, in accordance with generally accepted professional standards.

   (I) Review and update all administrative directives and medical care guidelines to ensure that they are comprehensive and current.

   (J) Ensure adequate training to all medical staff in issues relevant to the care of individuals with developmental disabilities, such as seizure management, fractures, decubitus ulcers, and code blues.

(K) Provide adequate and regular review and tracking of all code blues by the code blue committee.

(L) Ensure that all clinical records are complete, accurate, organized, and sufficiently detailed to provide for continuity of care. Ensure that the front of each resident's chart contains a complete and accurate problem list.

(M) Ensure accurate and thorough seizure reporting according to generally accepted professional standards.

(N) Ensure that health maintenance testing on all residents is completed, tracked, and charted in a thorough and organized fashion.

(O) Establish a formalized mechanism for identifying each resident with nutritional and physical support needs, including but not limited to persons who are at risk of choking/aspirating, have swallowing difficulties, require assistance to eat or drink, or receive enteral feedings or are a candidate to do so. Develop criteria for resident referral to the dysphagia team and include these criteria in the facility's policies and procedures.

(P) Ensure that a qualified interdisciplinary dysphagia team proactively addresses nutritional and physical support needs for those residents who require them. The team should meet regularly for review and should include, at a minimum, representatives from the disciplines of nursing, medical care, nutrition, psychology, occupational therapy, speech therapy/dysphagia, respiratory therapy, and physical therapy.

(Q) Ensure that comprehensive assessments are completed for each resident with identified nutritional and physical support needs. Each assessment should result in an individualized action plan that should be incorporated into the resident's individualized program plan.

(R) Ensure that comprehensive assessments are completed for residents to determine whether they

are receiving adequate seating, alternate positioning, and augmentative and alternative communication ("AAC") where necessary, and provide the services required according to the assessments.

(S) Ensure that the dysphagia team provides specific, competency-based training to direct care staff on the implementation of each resident's individualized program plan.

(T) Provide occupational and physical therapists, speech language pathologists, and rehabilitation engineering staff with training in seating assessment.

(U) Provide occupational and physical therapists, speech language pathologists, and rehabilitation engineering staff with training in alternate positioning methods and devices.

(V) Provide occupational and physical therapists, speech language pathologists, and rehabilitation engineering staff with training in AAC.

(W) Ensure development of improved systems for assessing each resident's need for a seating system, alternate positioning, and AAC use. These systems should include a mat exam and provide documented outcomes to be achieved.

(X) Establish a routine system for monitoring physical supports, seating, alternate positioning, and AAC devices to ensure ongoing staff competency as well as appropriate support for each resident's identified goals and to ensure they are safe and adequately maintained.

(Y) Ensure that all OT/PT and direct care staff are provided competency-based training which addresses the provision of physical assistance supports when working with individuals with developmental disabilities including, at a minimum, training in body mechanics, lifting, transfers, and appropriate alignment and support for seating and alternate positioning.

(Z) Provide additional competency-based and person-specific mealtime training that addresses specific mealtime assistance strategies to include alignment and positioning and presentation of food and fluids using adaptive equipment.

(AA) Ensure that each resident identified with person-specific mealtime needs be provided a written mealtime support plan.

(BB) Institute a system for monitoring the staff's implementation of each mealtime support plan.

(CC) Provide staffing levels for occupational therapy, physical therapy, and speech language pathology which are adequate to ensure that thorough and appropriate assessments are completed to identify needs in each discipline.

(DD) Develop and provide a comprehensive individualized assessment of each resident who is in need of occupational therapy, physical therapy, speech therapy, assistive technology, and mealtime and physical assistance supports. Ensure that therapists' assessments identify individualized functional outcomes for therapy supports and services.

(EE) Ensure that all residents with therapy needs identified through the assessment process receive appropriate supports and services according to generally accepted professional standards.

D. <u>Serving Persons in the Most Integrated Setting</u>

1. Provide services to individuals with developmental disabilities in the most integrated setting appropriate to their needs. To this end, the facility shall take these steps:

(A) 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. Ensure that those performing these assessments have adequate information regarding community-based options for placements, programs, and improvement.

(B) 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.

(C) Develop and implement a protocol to address outstanding issues and concerns with the State's regional centers that may impede, limit, or delay placement of residents into more integrated community settings. Develop and implement a protocol to reform the IPP process to better ensure that the teams make informed and proper decisions with regard to the most integrated setting for each resident.

(D) Ensure that consent decisions are fully informed.

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

* * *

We hope to continue working with the State in an amicable and cooperative fashion to resolve our outstanding concerns with regard to Lanterman. 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 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.

We are obligated to advise you that, in the unexpected event that we are unable to reach a resolution regarding our concerns, within 49 days after your receipt of this letter, the Attorney General is authorized to initiate a lawsuit pursuant to CRIPA, to correct deficiencies of the kind identified in this letter. See 42 U.S.C. § 1997b(a)(1). We would very much prefer, however, to resolve this matter by working cooperatively with you.

Accordingly, we will soon contact State officials 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,

Wan J. Kim
Assistant Attorney General

cc: The Honorable Bill Lockyer
Attorney General

Clifford Allenby
Director
Department of Developmental Services

Alan Madeiros
Executive Director
Lanterman Developmental Center

Debra W. Yang
United States Attorney
Central District of California