December 11, 2006

The Honorable Rick Perry
Office of the Governor
State Insurance Building
1100 San Jacinto
Austin, TX 78701

Re: CRIPA Investigation of the Lubbock State School
Lubbock, Texas

Dear Governor Perry:

I am writing to report the findings of the Civil Rights Division's investigation of conditions at the Lubbock State School ("LSS"), in Lubbock, Texas. LSS is a residential treatment facility for persons with developmental disabilities that is owned and operated by the Texas Department of Aging and Disability Services (known as "DADS"). On March 17, 2005, we notified you of our intent to conduct an investigation of LSS pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. As we noted, CRIPA gives the Department of Justice authority to seek relief on behalf of residents of public institutions who have been subjected to a pattern or practice of egregious or flagrant conditions in violation of the Constitution or federal law.

During the week of June 13, 2005, we conducted an on-site inspection of LSS with expert consultants in psychiatry, psychology (including habilitation and skills training), general medical care, nursing, nutritional and physical management, protection from harm, and community placement. Before, during, and after our site visit, we reviewed medical and other records relating to the care and treatment of LSS residents.[1] We also reviewed facility policies and procedures, interviewed administrators and staff, and observed residents in their residences, activity areas, classrooms, workshops, and during

[1] In particular, 17 LSS residents have died since our visit, and we have reviewed the available records associated with those deaths.

meals. Consistent with our commitment to provide technical assistance and conduct a transparent investigation, we conducted an exit conference with facility staff to convey our preliminary findings.

As a threshold matter, we note that LSS is staffed predominantly by dedicated individuals who are genuinely concerned with the well-being of the persons in their care. We wish to express our appreciation for the assistance and cooperation provided to us by LSS administrators and staff throughout the investigation.

During our on-site tour, LSS housed 344 residents aged 15 to 75 years old. Residents live in 16 housing units spread across the facility's 226-acre campus. Almost three-fourths of the residents have a diagnosis of severe/profound mental retardation; about one-half suffer from seizure disorders; and one-third have significant ambulation difficulties. Most residents also have a severe communication disorder. A number of residents have significant behavioral issues and receive psychotropic medications. In general, most residents require substantial staffing supports to meet their daily needs.

I. FINDINGS

Individuals with developmental disabilities in a state institution have a Fourteenth Amendment due process right to reasonably safe conditions of confinement, freedom from unreasonable bodily restraints, reasonable protection from harm, and adequate food, shelter, clothing, and medical care. Youngberg v. Romeo, 457 U.S. 307 (1982). See also Savidge v. Fincannon, 836 F.2d 898, 906 (5th Cir. 1988) (finding that Youngberg recognized that an institutionalized person "has a liberty interest in 'personal security' as well as a right to 'freedom from bodily restraint.'"). Determining whether treatment is adequate focuses on whether institutional conditions substantially depart from generally accepted professional judgment, practices or standards. Youngberg, 457 U.S. at 323. Residents also have the right to be treated in the most integrated setting appropriate to meet their individualized needs. See Olmstead v. L.C., 527 U.S. 581 (1999); Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. §§ 12132 et seq.; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; 28 C.F.R. § 35.130.

We found that LSS substantially departs from generally accepted professional standards of care in that the facility fails to: (1) provide adequate health care (including nursing

services, psychiatric services, general medical care, pharmacy services, dental care, and occupational and physical therapy, and physical and nutritional management); (2) protect residents from harm; (3) provide adequate behavioral services, freedom from unnecessary or inappropriate restraint, and habilitation; and (4) provide services to qualified individuals with disabilities in the most integrated setting appropriate to their needs.

A. Health Care

1. Medical Services

Generally accepted professional standards for the provision of health care, particularly for individuals with fragile health, (such as many of LSS's residents) require a process in which there is early identification of changes in health status, prompt evaluation to determine the cause, timely initiation of appropriate interventions, and ongoing monitoring to prevent future recurrence. LSS's provision of health care falls alarmingly short of professional standards of care. More specifically, LSS's failure to provide timely interventions to avoid, or minimize the effect of, acute problems has led to tragic outcomes.

To date, 17[2] LSS residents have died since our June 2005 tour. Our review of a number of these deaths raise concerns regarding the quality of care that LSS residents receive. In one disturbing incident, in [date redacted in public document] 2005, a medical code was called for LSS resident N.L.U. in response to the staff noting that she was not breathing, cool to the touch, and had no pulse. A call for LSS medical assistance was made at 5:36 a.m., but outside emergency medical services ("EMS") were not notified for several critical minutes, until 5:43 a.m. Further, the EMS report stated that upon arrival, N.L.U. had rigor mortis to her jaws, indicating that she probably had died hours earlier. She was pronounced dead at 6:10 a.m.

LSS's records indicate that two LSS staff members actually had found N.L.U. unresponsive around 5:00 a.m., and "panicked"; they did not assess her breathing or her pulse, and failed to

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[2] K.N., U.C., N.L.U., I.N., E.D., T.C., K.E., G.S., M.E., K.B.Q., G.N., Q.X., U.T., M.N., I.X.D., S.I., and U.K. have died since our tour. Throughout this letter, we have assigned initials other than residents' actual initials to protect their identity. We will provide separately a schedule by which these residents can be identified.

initiate CPR.[3] Also, they waited approximately 30 minutes before initiating a medical code. Further, LSS's documentation indicates that, when additional staff were summoned to N.L.U.'s room, one of the staff members who found her unresponsive refused to assist in placing her on the floor to begin CPR because she "could not go back into that room." Separately, the facility's subsequent investigation determined that staff had falsified bed check sheets, diaper changing sheets, and the log book so that these records wrongly stated that all individuals under their care, including N.L.U., were checked, repositioned, and changed at 5:30 a.m., 5:45 a.m., and 6:00 a.m. Given that N.L.U. reportedly was found dead about 5:00 a.m., she obviously could not have been checked, repositioned, and changed on multiple occasions thereafter. At least one staff person was disciplined for neglect in connection with N.L.U.'s death.

We cannot determine if prompt resuscitation efforts would have changed events. However, the failure to initiate such efforts for at least 30 minutes after N.L.U. was discovered virtually ensured the outcome. The staff members involved were noted to have had basic CPR training, but they had not undergone medical emergency drills to demonstrate their ability to perform the procedures.

a. Nursing Services

Nursing services at LSS are inadequate. The general approach to nursing at LSS is reactive, responding to known or apparent health problems only when they reach acute status, rather than providing timely interventions to prevent or mitigate the occurrence of acute problems. Consequently, LSS residents are placed at substantial risk of grave harm.

More particularly, our review of individual records showed that nursing care plans are general and vague, do not address individuals' health status and do not include necessary interventions to treat illness and prevent recurrence of illness. Also, recommendations in nursing care plans fail to specify the signs and symptoms that must be monitored. Further, nursing care plans for individuals at high risk do not identify individualized interventions related to identified risk factors.

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[3] N.L.U. had a number of known, serious medical conditions warranting that she be cared for by staff competent in at least basic health care, including first aid.

Independent of the weaknesses in nursing care plans, nurses in practice do not provide consistent monitoring and complete documentation regarding chronic health care issues, such as constipation and aspiration, that can be life-threatening for persons with compromised health, as is the case for many LSS residents. In addition, although this issue is not exclusive to nursing, there is also an almost total lack of preparation of the staff regarding medical emergencies.

Overall, the deficiencies in nursing relate to the shortcomings in staffing (discussed further below), the lack of a system to guide care, and the competency of the nurses on duty. These shortcomings place residents at great risk of harm.

Many of the foregoing deficiencies are illustrated in the death of E.D. According to LSS's records, E.D. was a 50-year-old LSS resident who died on [date redacted in public document] 2006, from aspiration[4] pneumonia. Strikingly, although E.D. had a history of significant gastrointestinal problems,[5] LSS failed to provide this individual with plans of care for these problems that nurses should implement. Further, our record review indicates that LSS failed to change E.D.'s diet in response to his gastrointestinal difficulties. In fact, he received snacks before bedtime, which clinicians should readily understand would make these difficulties worse. Further, although his records make clear that E.D. consistently had an increase in behaviors associated with pain in the two hours following meals, we found no evidence that his symptoms were ever assessed or addressed. In summary, the evidence is compelling that E.D. was not adequately monitored for changes in his health status that made him susceptible to aspiration, nor was he provided with appropriate supports to minimize the risks of aspiration. His death from aspiration pneumonia is highly troubling.

On [date redacted in public document] 2005, LSS resident Q.X. died of respiratory failure from recurrent aspiration pneumonias. Q.X. received all nutrition by tube and had a significant history of aspiration pneumonias. He was sent to the

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[4] "Aspiration" is the entry of secretions or foreign material, often food, into the trachea and lungs.

[5] These problems included gastroesophageal reflux disease ("reflux" or "GERD"), damage to the esophagus from stomach acid ("Barrett's esophagus"), chronic inflamation of the stomach lining ("gastritis"), and stomach protrusion into the chest cavity ("hiatel hernia").

infirmary for respiratory distress, lowered oxygen saturations,[6] and rales noted to both lobes.[7] Notwithstanding these significant health issues, his medical chart contained few nursing entries that noted Q.X.'s vital signs,[8] lung sounds, and his overall health status. Q.X. was then transferred to the community hospital and two days later was placed in intensive care due to respiratory failure. He also was diagnosed with aspiration pneumonia. His condition worsened over the ensuing weeks, and his family authorized a withdrawal of treatment. Shortly thereafter, on the 25th day of hospitalization, he died.

The lack of documentation in Q.X.'s case is not isolated. Nurses at LSS routinely fail to obtain an individual's vital signs when appropriate. For example, nurses document vital signs incompletely or simply write "within normal limits" for individuals who should have had objective measurements of their vital signs documented in their charts. Designations "within normal limits" fail to provide specific critical information by which to make health decisions. Separately, nurses fail to record lung sounds for individuals with identified respiratory problems. LSS's practices do not produce meaningful data about health status and impair the staff's ability to provide acceptable health care.

Further evidencing a lack of attention to individuals' health conditions, we discovered that, even after a LSS resident suffered a serious skin breakdown, nurses failed to monitor this individual's skin, and a second decubitus ulcer developed. The resident suffered unnecessarily due to the failure to take precautions to prevent the second sore.

Separately, LSS's nursing department has no system in place to analyze medication variances and identify trends. Nor does LSS have an effective infection control program. In this regard, we found no monthly or yearly analyses of infections occurring at LSS. In addition, we observed an absence of necessary steps to reduce infection in the infirmary, including adequate hand

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[6] "Oxygen saturation" refers to the amount of oxygen carried in blood cells.

[7] "Rales" refers to lung sounds that indicate possible aspiration pneumonia or pneumonia. "Lobes" refers to the upper and lower lobes of the lung.

[8] "Vital signs" are temperature, pulse, respiration and blood pressure readings.

washing, which was also a problem throughout the facility. More fundamentally, LSS's nursing programs conduct no internal audits to identify areas of strength or weakness.

We are compelled to note that a fundamental cause of these deficiencies is staffing. During our visit, the LSS nursing department had 14 vacancies for nursing positions (five positions for licensed vocational nurses and nine positions for registered nurses.) There was a consensus among the medical director, the director of nursing, and the psychiatrist that the nursing department badly needed nurses to provide consistent care to individuals.

b. Infirmary

The care and services that LSS provides to medically fragile individuals in the infirmary is inadequate and places those individuals at risk of harm. During our visit, individuals housed in the infirmary were either sitting in the hallway or lying in bed looking at the ceiling. The absence of meaningful activities and active treatment at the infirmary is due in large part to the dangerously low staffing levels provided there. During our visit to LSS, the newly assigned nurse manager indicated that there were two vacant registered nurse positions and too few direct care staff to provide necessary services.

In addition, lack of competence among LSS's staff has placed residents at risk. For example, staff may have contributed to the spread of serious infections because they were unfamiliar with infection control procedures for caring for individuals with MRSA[9] and did not know which individuals required isolation precautions. Similarly, staff did not know resident meal plans and physical positioning plans, which are necessary to maintain safe mealtime practices and appropriate body alignment. Because many infirmary residents have a high risk of aspiration or have

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[9] MRSA ("methicillin-resistant staphylococcus aureus") is a bacteria resistant to certain antibiotics, including methicillin, oxacillin, penicillin, and amoxicillin. Centers for Disease Control and Prevention, at http://www.cdc.gov/ncidod/hip/Aresist/ca_mrsa_public.htm. MRSA manifests itself as a boil or sore on the skin and is spread through contact with an infected person or a surface the person has touched. Id. In some cases, MRSA can have serious medical consequences, for example, by causing surgical wound infections, bloodstream infections, and pneumonia. Id.

recently been treated for aspiration pneumonia, staff's unfamiliarity with their care plans places these residents at increased risk of harm.

Moreover, the infirmary was not well-equipped to serve the needs of medically fragile residents. For example, wheelchairs were not properly cleaned, and inadequately sized sheets exposed residents to risk of a skin breakdown from plastic mattress covers. In fact, as of our visit, five infirmary residents had skin breakdown or decubitus ulcers, which are painful and dangerous health conditions. In another instance, staff in the infirmary was unable to locate the communication device for K.D., thereby depriving the resident the benefit of using it. Even more fundamentally, emergency equipment was not monitored to ensure that it was functioning properly. We discovered two oxygen tanks designated for use at the infirmary that were empty. This lapse in monitoring places infirmary residents, many of whom have respiratory ailments, at risk of harm.

c. Physical and Nutritional Management

LSS does not provide individuals with physical and nutritional management care consistent with generally accepted professional standards. Individuals at LSS with dysphagia (swallowing difficulty) and those at risk of aspiration are not provided adequate assessments or interventions to address these conditions. Although there is a physical and nutritional management team ("PNMT") at LSS, none of its members have had specialized training in developing physical and nutritional management programs for residents. Further, the PNMT has not identified all LSS residents in need of services, and has not developed categories to prioritize those with the most serious needs for treatment. There is no system in place to: (1) document an evaluation, or trigger an evaluation, of residents who gag, cough, or choke on food or fluids; (2) alert the PNMT that such an event has occurred or that the individual involved may need a reassessment and possible program modification; or (3) determine whether programs are effectively treating individuals. Even LSS residents who have suffered aspiration are not provided a comprehensive reevaluation to assess the appropriateness of their PNMT plan.

Meal plans we reviewed were difficult to read and lacked clear instructions for staff. Our assessment, which is also supported by LSS mealtime monitoring reviews, is that meal plans are not followed, positioning is not implemented on schedule, and adaptive equipment is not available. Moreover, the monitoring is insufficiently individualized, does not occur often enough to

detect in a timely way when program modifications are required, and does not consider additional settings where swallowing difficulties may occur, including during hospital visits. The deficiencies we identified in physical and nutritional management place individuals at LSS at risk of significant harm.

For example, G.N. was a 45-year-old, nonverbal, nonambulatory male who had a significant number of episodes of aspiration pneumonia, pneumonia, and respiratory distress dating from 1993. On [date redacted in public document] 2006, G.N. died at a local hospital. The documentation indicated that his death was related to severe respiratory failure secondary to pneumonia. G.N. had a percutaneous endoscopic gastronomy (commonly referred to by clinicians as a "PEG") feeding tube, a jejunal feeding tube ("J tube"), and a gastrostomy feeding tube ("G tube") placed in 1999 due to aspiration and chronic bouts of vomiting. Further, a swallowing study demonstrated that he was experiencing a "swallowing dysfunction." In addition, from February 2005 to December 2005, LSS's documentation indicated that G.N. had experienced eight incidents of respiratory illnesses such as bronchitis, aspiration pneumonia, and pneumonia. Notwithstanding this history, we could find no indication in LSS's records that the PNMT had re-assessed G.N. after his respiratory episodes to ensure his positioning and treatment plan were adequate to meet his serious and well-known needs.

In the period before his death, G.N.'s progress notes indicated that he frequently experienced coughing, a decrease in his oxygen saturations, increases in his pulse and respirations, and difficulty breathing. However, there was no indication that any objective clinical data were regularly monitored and documented, such as routine lung sounds, oxygen saturations, and vital signs, as part of a treatment plan to monitor G.N. for risk of aspiration. In fact, his latest physical and nutritional management plan ("PNMP"), dated October 6, 2005, stated that the plan's focus was preventing fractures from osteoporosis and preventing complications from aspiration and reflux. Yet, notwithstanding his clearly compromised condition and his numerous recent incidents of respiratory illness, the PNMP identified no interventions by which fractures or complications from aspiration/reflux were to be prevented. Strikingly, the section titled "Review" stated that "[h]is PNMP has been successful, as he has had no known reports of injury," and the recommendations indicted that G.N. was not to be re-assessed until the following year. G.N.'s multiple respiration illnesses strongly suggested that the plan actually was not working and that G.N. should have been reassessed promptly.

Q.X. was a 36-year-old male with a history from the late 1980s' of many aspiration pneumonias. Q.X. was fed by tube and took nothing by mouth. We could find no indication in his medical record that his vital signs, oxygen saturations, lung sounds, or respiratory rates were regularly monitored and documented. Notwithstanding Q.X.'s history of aspiration pneumonia, LSS had no interventions in place to regularly monitor and document his health status. On [date redacted in public document] 2005, he was noted to have labored breathing with rales in both lobes. He was noted to be moaning and his oxygen saturation dropped to 88%.[10] He was first transferred to the facility's infirmary and later to the community medical center, where he died of recurrent aspiration pneumonia on [date redacted in public document] 2005. His record strongly suggests an absence of appropriate care regarding the conditions that led to his death.

d. Physical and Occupational Therapies

LSS residents are not receiving adequate physical therapy ("PT") and occupational therapy ("OT") services to meet their needs. Our review of resident charts and observations made during visits to cottages, mealtime settings, and programs, form the basis of our finding that significant numbers of individuals have serious unmet needs in these areas. There are few PT or OT therapists on staff to serve the 344 residents, and the existing therapists do not monitor the quality or consistency of PT or OT program implementation by direct care staff. PT and OT assessments fail to consider or describe critical variables that assessments should address. If an individual has a new need, LSS has no system in place to inform the therapists or to trigger a PT or OT assessment or intervention. Particularly concerning is LSS's practice of having ambulatory individuals sit in a wheelchair, ostensibly to prevent falls and to facilitate transport. This is not an accepted practice and leads to regression of ambulation skills.

e. General Clinical Care

Medical services at LSS are provided by the full time Medical Director and two full time physicians, supplemented by specialty clinicians in the fields of neurology, dermatology, podiatry, urology and ENT (Ear, Nose, and Throat). Chart reviews, interviews, and observations indicate that, once an acute change in health status is identified, LSS medical staff

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[10] Oxygen saturation levels near 100% are normal.

provide timely interventions and appropriate documentation about the individual. Nevertheless, certain critical components of a systemic health care plan are not in evidence at LSS: there is no medical peer review system, i.e., no medical quality improvement system to assess data on medical services, and no system to identify medical trends and outcomes. These deficiencies prevent the facility from identifying issues after the fact and correcting underlying causes to prevent future recurrence.

For example, we noted that several patients received "stat"[11] doses of pain medication, but were not subsequently analyzed either as to the effect of the pain medication or the possible masking of an underlying medical condition. This is particularly problematic, given that most of LSS's residents have significant communication deficits and cannot easily report health problems. Further, there is no formal interdisciplinary process to identify individuals who are at high risk for medical concerns. Without the establishment of such systems to assess and monitor individuals' health status, and to analyze healthcare at LSS, facility health providers are compelled to react to significant, but foreseeable health problems that could be avoided or mitigated. Consequently, they are unable to adequately serve the health care needs of LSS's residents.

f. Neurology Services

LSS provides adequate services to address the needs of individuals with neurological disorders. Such individuals are regularly seen and many of them have fairly well-controlled seizure-related conditions. We note that required blood levels are routinely obtained and recorded in neurology notes.

g. Pharmacy Services

LSS's pharmacy services are adequate regarding packaging, labeling, and disposition of all medications. However, there are significant deficiencies in the pharmacy reviews necessary to alert the medical staff to issues involving drug interactions, and follow-up laboratory or medical tests. Specifically, no meaningful information is provided by the pharmacist on Quarterly Drug Regimen Reviews ("QDRR"). In our review of over 300 QDRRs

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[11] "Stat" is a medical term meaning "immediately," often as an emergency, and is derived from the Latin word "statim," which also means "immediately."

prepared between March and May 2005, we found no mention of any problems regarding residents' medication – a finding unsupported by data in other LSS records. For example, the QDRRs did not identify lab results identifying abnormal or sub-therapeutic values, even though such results were noted in resident charts. The medication reviews provided by the pharmacy are inadequate and place residents at risk of harm. Although these duties are standard responsibilities of pharmacists in ICF/MR facilities like LSS, the LSS pharmacy does not routinely address these needs.

h. Dental Services

In contravention of generally accepted professional standards of care, resident medical charts lack a comprehensive dental assessment by which to determine whether appropriate dental services are provided to residents. We were told during our visit that dental x-rays are done on some residents but not on others, an approach that appears arbitrary. Also, as discussed more extensively at section I.A.2.d below, the continuing use of sedating medications for dental procedures, especially in view of the absence of any de-sensitization program, is problematic. Additionally, there are no records kept at LSS regarding the use of restraints or manual holds during dental procedures. Nevertheless, it is important to note that we found an adequate response by dental practitioners when individuals complained of tooth pain; records confirm that those persons were seen either on the day of the complaint or the next day.

2. Psychiatric Services

LSS does not provide adequate psychiatric services to residents with mental illness. This finding is a serious concern because of the number of residents currently identified as needing psychiatric services (approximately 200 individuals) and the reported trend at LSS to admit increasing numbers of persons with mental health issues. We found evidence that the deficiencies in psychiatric services at LSS extend across several components critical to providing adequate care, including: psychiatric assessments, psychiatric diagnoses, medication management, use of "pre-medications," individual and group therapy, and collaboration between psychiatry and neurology.

a. Psychiatric Assessments

Minimum professional standards of care call for a careful process of collecting and assessing relevant information to

determine an appropriate psychiatric diagnosis. However, none of the 31 psychiatric assessments we reviewed contained the necessary components of a standard psychiatric assessment. Chart review confirmed that LSS's psychiatrists do not adequately consider individuals' medical issues, physical injuries, family and psychiatric history, and comprehensive medication regime when attempting to determine the correct psychiatric diagnosis. Because professional staff does not fully consider critical factors such as these, the resulting assessment is incomplete and possibly inaccurate.

b. Psychiatric Diagnoses

Our review evidenced that many LSS residents have been identified as having psychiatric disorders based on vague diagnoses that do not comport with professional standards and do not appropriately inform treatment decisions. In fact, in 26 of 31 records reviewed, it was not possible to discern the psychiatric diagnosis for the mental condition being treated. Similarly, the charts of D.T., N.N., and E.C. listed Axis I[12] psychiatric diagnoses that were not acceptable under the Diagnostic and Statistical Manual of Mental Disorders ("DSM"), the accepted standard for psychiatric diagnostic criteria. Separately, LSS's psychiatric records demonstrate a consistent lack of clinical documentation to justify the mental health diagnoses that are provided.

A number of interrelated factors contribute to the facility's problems in developing adequate psychiatric diagnoses. First, the one full-time psychiatrist at LSS has a caseload of 180 residents. With this caseload, the psychiatrist must depend heavily upon information provided by direct care staff to diagnose his patients. However, direct care staff lack adequate training in basic mental health issues, including what symptoms and side effects to monitor, and how to monitor them. In this regard, the psychiatrist does not routinely inform the individual's interdisciplinary team ("IDT")[13] of the clinical

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[12] "Axis I" mental health diagnoses are those identified by the Diagnostic and Statistical Manual of Mental Disorders in a broad class of "clinical disorders," such as delirium, schizophrenia and other psychotic disorders, mood and anxiety disorders, and sleep disorders.

[13] The IDT is composed of the facility staff members assigned from each discipline, such as occupational therapy,

(continued...)

justification for mental health diagnoses. As a result, the members of the IDT do not know what symptoms to track to provide objective data on treatment efficacy.

Diagnoses drive treatment interventions, including medication choices. The absence of sound diagnoses exposes LSS's residents to counterproductive, even harmful, interventions, and to interventions that mask but do not correct underlying disorders. LSS's failure to provide clinically justified psychiatric diagnoses constitutes a substantial departure from generally accepted professional standards of care that exposes its residents to harm.

c. Medication Management

To assess individuals' mental health status and the effectiveness of their treatment, facilities like LSS typically utilize professional treatment review teams. The LSS Psychotropic Review Clinic has functional flaws: it emphasizes a discipline-specific approach, is fragmented, and omits the views of the individual's IDT. Although the psychiatrist appears to be seeing residents on rounds (and making medication adjustments at that time), there do not appear to be any established criteria in place that would trigger psychotropic reviews when necessary. Separately, treatment choices frequently do not appear to be substantiated by the assigned diagnosis. For example, S.E. received antipsychotic medication to treat a movement disorder involving self-injurious behavior. There was no documentation in his record to justify clinically this choice of treatment.

Also, we could not find evidence of appropriate oversight of medication usage by LSS's residents, including consideration of potentially more appropriate medications. For example, there was no documentation to indicate that S.E. was seen in the Psychotropic Review Clinic to review the stabilization of his glucose level after a medication change or to consider use of another medication, as had been recommended in his psychiatric consultation. Nor was there any indication that the IDT had discussed his case. LSS's failure to provide regular medication follow-up based on residents' needs is a substantial deviation

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[13] (...continued)
direct care, and nursing, providing supports and services to the individual. The members of the IDT are responsible for working in collaboration to ensure that the individual's care needs are met and typically are the staff members at the facility who are most familiar with the individual.

from accepted professional standards of safe medication practices and places the residents at significant risk of harm.

d. "Pre-Medications"

LSS utilizes "pre-medications" (sedatives administered to individuals prior to medical or dental procedures) to control residents. Although pre-medications are sometimes necessary, at least on a short-term basis, LSS's use of pre-medications is problematic. Most significantly, the facility does not systematically monitor the use of such medications. Consequently, it cannot reliably track the efficacy of the medications on particular individuals, the frequency with which individuals are medicated with these drugs, and the consequential side effects, including interactions with other medications, falls, injuries, and reduced cognition. In this regard, psychiatrists are not consistently informed when their patients receive pre-medications, although pre-medications can skew the results of a mental status examination and cause behavioral problems. Separately and more fundamentally, we did not see evidence that de-sensitization programs were in place at LSS to help diffuse individuals' fear of procedures and eventually reduce the need for pre-medication. LSS's pre-medication practices constitute a substantial departure from generally accepted professional standards of care that expose individuals to harm.

e. Individual and Group Therapy

Accepted standards of psychiatric practice require that persons with mental illness are assessed to determine their need for treatment. There is no system at LSS to ensure that individuals are assessed, evaluated, and referred for individual or group therapy. Chart reviews at LSS indicated that only three individuals of the 200 identified with mental illness receive therapy. Individuals with a clear need for psychotherapy at LSS were not referred for treatment. These included persons who have experienced abusive and traumatic events. Failure to provide necessary treatment places LSS's residents at risk of substantial harm.

f. Collaboration between Psychiatry and Neurology

LSS lacks a formal system for collaboration between psychiatry and neurology staff on safe medication practices for individuals with co-occurring seizure and mental health disorders. This is a substantial deviation from accepted

standards of care and places individuals at risk of harm. Specifically, the side effects of medications in both areas can have a far-reaching impact on the individual's health and behavior. Without a system in place to exchange information between these two disciplines, treatment altered by one specialty could destabilize treatment from the other specialty.

B. Protection from Harm

LSS fails to provide basic oversight of resident care and treatment critical to ensuring the reasonable safety of its residents. As described in more detail below, LSS's failure to protect residents from harm stems from inadequate supervision, the failure to appropriately detect and prevent abuse and neglect, and an inadequate incident management system. Consequently, residents are exposed to significant harm.

1. Inadequate Supervision and Neglect

Our review of facility incident reports and investigations confirmed that residents are being subjected to a wide-spread pattern of harm due to inadequate supervision, neglect, and possible abuse. The circumstances surrounding the death of N.L.U. (described in more detail at section I.A.1 above), in which staff failed to call for immediate medical attention, failed to assist with basic first aid, and falsified records, evidence significant neglect. Other examples we identified include:

- On May 5, 2005, a staff person who was assigned one-to-one supervision to E.S. failed to notice that E.S. had fastened a belt around his neck. According to LSS's records, this occurred when the lights were off in E.S.'s room, two televisions were on, and the staff person was using her personal cell phone.

- On May 9, 2005, C.S. was discovered to have two decubitus ulcers on her buttocks and another on her shoulder. These sores, according to LSS's own records, were a result of workers not changing C.S.'s position and leaving her lying in urine-soaked diapers.

- N.P. has PICA (an eating disorder involving the mouthing or ingestion of non-food substances). Notwithstanding the identified need to protect N.P. from ingesting nonedible items, facility records indicate that N.P. repeatedly has been discovered chewing or eating harmful objects. For example, on

April 18, 2004, staff discovered N.P. chewing on a piece of gel cushion; on September 28, 2004, during a "diaper check," staff discovered a glove coming out of N.P.'s rectum; and on October 25, 2004, a "foreign body" was discovered in N.P. during an x-ray.

- On February 18, 2004, M.K. had an x-ray to determine if he had a high fecal impaction. The x-ray confirmed the impaction and also revealed that M.K. had ingested a button. Examination of his clothing revealed several buttons were missing from his shirts. LSS had removed clothing with buttons from M.K.'s wardrobe but did not address the adequacy of his supervision.

- On either June 6, 2005 or June 7, 2005, Q.D. was found with a 1/5" cut to his face and two black eyes. No one reportedly witnessed the cause of the injuries. The LSS investigation included a report stating that other individuals in the same home had had bruises or injuries during the same approximate time period, but incidents that may have caused bruising and injuries had never been seen. Individuals sustaining injuries were unable to explain what happened. Multiple staff members, including direct care staff and management staff, stated to us during our visit that "most" of the approximately 23 residents in the home were intimidated or frightened by a particular male staff member assigned to this home on the 2:00 p.m. - 10:00 p.m. shift. This staff person reportedly has been investigated in the past for similar incidents and was always working within the time frame of the reported injuries. We did not see evidence that LSS took action in response to these residents' concerns or the pattern of injuries and staff assignments.

As of the time of our visit, 66% of the population at LSS has been injured by another resident badly enough to require more than first aid. Almost 50% of the population was injured by another peer at least one time from April 2004 to April 2005. Individuals at LSS continue to be at risk of resident-to-resident injuries, including human bites and fractures. Seventy-three residents (21% of the LSS population) have been injured from their peers' bites, and 41 of these residents (56%) required medical attention as a result.

Even in instances where known behavioral risks have been communicated, staff were unable to respond adequately. This is particularly evident in cases of residents causing injuries to

other residents. For example, U.K.T. was bitten by other residents 26 times between May 2003 and May 2005. One resident was responsible for 16 of those bites, while another resident caused five bites. As a result of these bites, U.K.T. required medical care to her face, wrist, forearm, upper arm, shoulder and back.

2. Inadequate Incident Management

Generally accepted professional standards of care require that facilities gather and assess incident data to identify potentially problematic trends, and to identify, implement, and monitor implementation of corrective action. Proper incident investigations are also a federal regulatory requirement. See 42 C.F.R. § 483.420(d)(2)-(4) (requiring that incidents be investigated and appropriate action taken).

LSS does not have an effective incident management and quality improvement system. For instance, LSS does not audit to confirm that significant resident injuries are reported for investigation. Many abuse and neglect investigation files that we reviewed indicated that staff had knowledge of an incident but failed to report it. Further, staff were not corrected for failing to report. A few examples of staff's failure to report abuse and neglect include:

- On February 7, 2005, S.H. ingested an orange neon rubber string while on one-to-one supervision. No incident report was ever filed, nor was an investigation opened regarding the staff's failure to supervise S.H. properly.

- On August 5, 2004, E.E. ingested stickers while she was supervised by one-to-one staff. Following this incident, staff also failed to file any written report or investigate neglect.

- On June 15, 2004, another LSS resident, E.N., ingested a nickel while on one-to-one supervision. Like the other residents mentioned above, there was no report of this incident or investigation of neglect.

These examples indicate that LSS is experiencing significant under reporting of incidents. Failure by staff to report abuse and neglect places residents at significant risk of immediate and future harm.

C. BEHAVIOR PROGRAMS, RESTRAINTS, AND HABILITATION

LSS's residents are entitled to "the minimally adequate training required by the Constitution . . . as may be reasonable in light of [the residents'] liberty interests in safety and freedom from unreasonable restraints." Youngberg, 457 U.S. at 322. LSS fails to provide adequate psychological services to meet the needs of residents with behavior problems. Specifically, LSS: (1) provides residents with ineffective behavioral programs; (2) exposes residents to undue restraints; and (3) provides inadequate habilitation treatment and activity programs.

Generally accepted professional practice requires that appropriate psychological interventions, such as behavior programs and/or habilitation plans,[14] be used to address significant behavior problems. However, many LSS residents who require psychological interventions are simply not provided them. As described in more detail below, LSS's deficiencies in this area substantially hinder treatment of residents' problem behaviors, exposing residents to a significantly increased risk of abuse, and compromising residents' opportunities for placement in a more integrated setting. The examples of injurious behavior set forth above, in addition to demonstrating inadequate supervision and neglect, also demonstrate significant weaknesses in LSS's behavioral programming.

1. Behavior Programs

Generally accepted professional standards of practice provide that behavior programs: (1) be based on adequate functional assessments; (2) be implemented as written; and (3) be monitored and evaluated adequately. Ineffective behavior programs increase the likelihood that residents engage in harmful and inappropriate ("maladaptive") behaviors, subjecting them to unnecessarily restrictive interventions and treatments. LSS's behavior programs are ineffective and substantially depart from generally accepted professional standards. In particular, they are not based on adequate functional assessments, not implemented as written, and are not monitored, evaluated, and revised adequately.

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[14] Habilitation includes, but is not limited to, individualized training, education, and skill acquisition programs developed and implemented by interdisciplinary teams to promote the growth, development, and independence of individuals.

For example, H.H. has been diagnosed with PICA. Her psychologist reports that, on October 8, 2004, she tore open the armrest of a recliner and attempted to eat the stuffing. She also has chewed on the edge of a dining room table, a bed sheet, and a piece of diaper. According to the psychologist testing H.H., boredom was the underlying cause, which indicates that H.H. does not receive adequate habilitation and training. H.H. has a behavior support plan ("BSP") to address these issues, but rather than modify the BSP, or ensure that it was properly implemented to address her boredom, H.H. was prescribed Zyprexa, an atypical antipsychotic medication, and the antidepressant Paxil.

a. Functional Assessment

Generally accepted professional standards of care for this population dictate that there is an adequate and current functional assessment in all cases prior to the initiation of psychological treatment. A functional assessment is a professional assessment technique that identifies the particular positive or negative factors that prompt or maintain a challenging behavior for a given individual. By understanding the causes, or "function," of challenging behaviors, professionals can attempt to reduce or eliminate these factors' influence, and thus reduce or eliminate the challenging behaviors. Without such informed understanding of the cause of behaviors, attempted treatments are arbitrary and ineffective.

The functional assessments developed by LSS's psychology staff are seriously deficient. They are somewhat arbitrary and fail to address highly relevant information, such as: (1) a resident's background, including social history and treatment experiences; (2) summary behavior data; (3) assessment tools used to determine the function of the behavior; (4) medical issues, particularly health problems that might influence the behavior; (5) mental health concerns, including clinical diagnoses and descriptions of clinical or behavioral manifestations associated with each diagnosis; and (6) recommended treatment/intervention that develop new skills and appropriate replacement behaviors that adequately substitute for the maladaptive behavior.

Without a thorough assessment of the function of the resident's maladaptive behavior, including clearly identified, appropriate replacement behaviors, behavior programs will not be successful in modifying the maladaptive behavior. As a result of LSS's incomplete assessments, numerous residents with behavioral difficulties, and other residents in their proximity, have remained at risk of harm due to ongoing behavior problems that are not treated effectively.

b. Behavior Program Implementation

Improper implementation of a behavior program can lead to the inadvertent reinforcement of maladaptive behaviors, as well excessive use of restrictive treatments. Throughout LSS, we observed numerous incidents of inadequate implementation of behavioral support programs.

Consistent and correct implementation of appropriate behavior programs is essential. However, as stated above, the written programs themselves are deficient, and the inconsistent implementation of these inadequate programs only magnifies these inadequacies, resulting in a level of care that is grossly inconsistent with generally accepted professional standards of care. This poor implementation of programming places LSS's residents with behavior problems at risk of continued harm, continued exposure to restrictive interventions, and continued institutionalization. Many of the problems stem from inadequate competency-based training of staff regarding the proper implementation of behavior programs.

c. Monitoring and Evaluation

Generally accepted professional standards of care require that facilities monitor residents who have behavior programs to assess the residents' progress and the program's efficacy. Without the necessary monitoring and evaluation, residents are in danger of being subjected to inadequate and unnecessarily restrictive treatment, as well as avoidable injuries related to untreated behaviors. In this regard, the injury data discussed above, particularly regarding human bites, provides strong evidence that plans are ineffective.

None of the behavior programs we reviewed specified the procedure used to monitor the resident or supervise staff implementation of the program, and none of the programs provided for measuring changes in replacement behaviors. Further, the safeguard of professional review and monitoring of behavior support services at LSS is woefully inadequate. Contrary to generally accepted professional standards of care, there is no professional review, prior to implementation, of BSPs by individuals with expertise in applied behavior analysis and in the development and implementation of behavior supports. We found no documentation evidencing a review of BSPs for appropriate content, completion, and protection of individual rights, including restraint reduction plans and informed consent for any restrictive practices, which again is contrary to generally accepted standards of care.

The Behavior Support Review Committee ("BSRC") review for Q.N., diagnosed with Alzheimer's, was limited to a review of her psychotropic medications and a statement that her problem behavior of aggression would be included in her BSP. There was no evidence of a review of the BSP itself, including whether it provided for monitoring of the behaviors which the psychotropic medication was intended to address ("target behaviors"), no consideration of assessment results, nor consideration of the hypothesized function of the problem behavior. There was also no discussion of the BSP's failure to identify any support for the Alzheimer's diagnosis.

d. Quality Assurance

There is no ongoing facility-wide tracking of critical aspects of psychological services at LSS, such as the use of restraints, the use of emergency procedures, the development and update of functional assessments, and staff implementation of programs. There is no systemic tracking and analysis of the type of restrictive components contained in BSPs. In fact, no one knew basic information such as the number of BSPs that had restrictive components.

Additionally, all of the BSPs we reviewed failed to provide precise strategies for measuring the effectiveness of the plan. The outcomes currently used by LSS to measure effectiveness are not indicators of a positive quality of life. Instead, there is a reliance on the frequency of problem behaviors. Although the BSPs all mention collecting data regarding the occurrence of problem behaviors, no plan addresses the methods used to ensure promotion of positive replacement behaviors, and we found none that monitors the individual's use of such behaviors.

There is also no systemic review of data reliability at LSS. Similarly, the accuracy of behavior data is suspect. In this regard, problem behaviors are often too poorly defined to be monitored accurately. For example, five different behaviors could be described as "aggression," and data are recorded as "aggression" when any of the five behaviors is exhibited. Cf. 42 C.F.R. § 483.440(e)(1) ("Data relative to accomplishment of the criteria specified in client individual program plan objectives must be documented in measurable terms"). Consequently, the collected data are not clinically useful.

e. Psychological Staffing

Lack of sufficient psychological and behavior support services is a significant cause of LSS's problems in this area. Although the Director of Psychological Services is a masters-level psychologist, trained and experienced in applied behavior analysis, there is an overwhelming lack of expertise in applied behavior analysis among the remaining members of the psychology department. The staff's inexperience is exemplified by many references in LSS's records to problem behavior occurring for "no reason." Separately, it appears that LSS's psychology staffing ratios are severely lacking; we note that the ratio of clinicians to residents is almost one-half of the generally accepted minimum ratio of 1:25 for a facility serving persons with developmental disabilities.

2. Restraints

LSS uses several types of mechanical restraints to control residents' behavior, including arm splints, helmets, posey mittens,[15] restraint chairs, restraint boards,[16] seatbelts, straight jackets, transport jackets, wristlets and anklets, and 4-point and 5-point restraints. Staff also often utilize physical and chemical restraints. Examples of physical restraints include manual holds involving hand, arm and leg, bear hugs, basketholds, and horizontal restraints. Chemical restraints consist of psychotropic medications administered in response to behavioral outbursts.

Generally accepted professional standards of care dictate that restrictive interventions such as these should be included in a behavior program only when justified by the results of an adequate functional assessment. Further, such intentions should only be used: (1) if the person poses an imminent and substantial risk of harm to themselves or others; (2) after a hierarchy of less restrictive measures has been exhausted or considered in a clinically justifiable manner; (3) continuously only if proven effective; and (4) other than as punishment, for

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[15] "Posey mittens" are similar to boxing gloves. They are made of canvas or plastic and secured at the wrist with velcro, metal slide buckles, or straps, and they serve to prevent the individual wearing them from using his or her hands.

[16] A padded, rigid board to which an individual is secured face-up. See LSS's Operational Procedures Manual, 6(g).

the convenience of staff, or in the absence of or as an alternative to treatment. Further, such interventions should be terminated as soon as the person is no longer a danger to himself or others.

LSS's use of restraints substantially departs from generally accepted professional standards of care and exposes residents to excessive and unnecessarily restrictive interventions. At least 58 residents' BSP includes manual holds. Fifty-three residents at LSS are subjected to mechanical restraints simply for undefined "inappropriate behavior." Helmets, restraint boards, restraint chairs, posey mittens, and arm splints are used as substitutes for professionally developed and implemented behavior programs. At least nine residents' BSPs include a provision for supine restraint on a restraint board. Another 15 residents are subjected to wearing a helmet to prevent access to their head, face, or mouth due to self-injurious behavior ("SIB") or PICA, and four of these helmets also have a face-guard. As of May 2005, 16 residents were subjected to Posey mittens - 9 for SIB and aggression, and another 6 as protective restraint to prevent injury. At least eight residents have application of arm splints or arm guards included in their BSP. In addition, six residents are subjected to wearing jumpsuits "to prevent aberrant behaviors." All of these residents are subjected to restraint without any restraint reduction plan, contrary to accepted standards of care.

Additionally, and contrary to generally accepted professional standards of care, LSS fails to monitor appropriately the use of restraints. This places individuals at LSS at significant risk for physical abuse, bodily injury, and neglect.

a. Mechanical Restraints

We found that non-medical restraints[17] were used without the support of data from a formal functional analysis or from a previous treatment trial with a less restrictive intervention. In many of these cases, restraints were implemented on an unplanned, emergency basis rather than as part of the residents' written behavior programs. Several residents are kept in

[17] Medical restraints, on the other hand, are restraints put in place initially for the resident's protection based on a medical reason, e.g., stabilization in connection with a medical procedure.

restraints for nearly all of their waking hours, regardless of whether they have exhibited the problem behavior. Some residents even sleep in restraints at night, when they are not a danger to themselves or others.

For example, J.D. was required to wear a helmet due to SIB for 24 days in February 2005, 26 days in March 2005, 23 days in April 2005, and 28 days in June 2005. Another example involves A.S., a 19-year-old man who has been at LSS since July 2003, and who wears a "collar" mechanical restraint (a device around his neck preventing him from bringing his arms to his mouth) 24-hours-a-day, even when sleeping, to prevent him from biting his arms. These examples strongly suggest that less restrictive measures either were not utilized prior to placing these individuals in restraints or were not implemented effectively.

We found that some highly restrictive interventions, such as two-point or four-point mechanical restraints, jumpsuits, or restrictive helmets with face masks, are labeled as "medical" restraints. Although these restraints may have been legitimately put in place initially for the resident's protection based on a medical reason, their use has continued for non-medical purposes, i.e., behavior control purposes. This indicates that the facility has failed to develop appropriate ways to treat residents' problem behaviors, and that staff utilize restraints either for their own convenience, or to control behaviors in lieu of effective behavioral treatment.

LSS's restraint release criteria are also contrary to standards of care. While accepted standards of care and federal regulations (42 C.F.R. § 483.450(d)(6)) provide that release is to occur every hour, residents at LSS have been restrained for hours without any release. For example, D.C. has had a plan since December 2003 and is subjected to Posey mitts contingent on SIB. However, she was mechanically restrained 3.5 hours without release for exercise. Another resident, T.X., has a plan for contingent use of a mitten restraint for SIB, to be applied for a minimum of 20 minutes to a maximum of one hour. B.B. was subjected to contingent use of a helmet and mittens at least 39 times in the past year, with the length of time restrained ranging from 15 minutes to 3.5 hours. Yet another resident, V.P. has been mechanically restrained as long as three hours and 45 minutes, at least two times, and two hours and 55 minutes, two times, from March 2004 to March 2005, without release for exercise.

b. Manual Restraint by Staff

We observed staff also engage in the practice of manual restraint, including the dangerous practice of prone manual restraint, which involves tight physical holds and often staff lying on top of residents who are face-down, on the floor. The use of extensive manual restraints on persons with developmental disabilities poses a significant risk of injury to the resident, as illustrated in the following examples:

- On February 6, 2005, E.S. was restrained for 11 minutes by 2 staff in a side-lying position. As a result, he sustained multiple scratches to his arms, wrists, shoulders, neck, middle of back, legs, ankles, and feet. In another incident, E.S. was restrained and suffered a scratch to his eyelid.

- On June 5, 2005, E.S. again was injured from restraints, scratching his nose and jaw during a "2-man sideline restraint so nurse could give him a shot." An incident report stated that staff then told E.S. that he could either "take [his medication] the hard way or the easy way." Reportedly, E.S. chose to "take it the hard way," and he was grabbed, choked, and thrown on the floor, slamming his face on the floor. He was administered an intramuscular ("IM") injection in response to refusing his medications and was bruised on his face and neck. (There was no documented evidence of a nurse assessment of these bruises at the time of the incident). The male staff who restrained E.S. told investigators that he was unable to restrain E.S. in the "proper" or "ideal" restraint because of the resistance. There was no documented evidence that the improper restraint was investigated or that the staff received follow-up training on appropriate restraint use. The following day, E.S. was once again restrained and suffered scratches to his shoulders, lip, temple and "top part of both legs."

The manner in which staff interacted with E.S. demonstrates a significant lack of knowledge regarding appropriate behavioral interventions. Repeatedly engaging individuals in physical confrontations and restraints in order to administer them medications is an extraordinary departure from generally accepted professional standards of care that places the individuals, and their staff, at significant risk of harm.

c. Chemical Restraints

Generally accepted professional standards dictate that chemical restraints should only be utilized as a last resort when other, less restrictive interventions have been ineffective. However, some residents at LSS receive chemical restraints on a regular basis. This practice strongly suggests that their behavioral treatment regimen is not adequate to address their behaviors. Forty residents at LSS are subjected to chemical restraints, often described by LSS as "emergency medications."[18] Further, the majority of BSPs reviewed contained a pro forma provision for the use of emergency medication in addition to mechanical/manual restraint: "[Name]'s BSP includes emergency medications 'after two restraints and still agitated.'" Chemical restraints, if used at all to control behavioral problems, should be prescribed only in unusual cases, to address specified and individualized behaviors, and for limited periods of time. Further, a physician should promptly conduct a face-to-face assessment of each individual receiving a chemical restraint. LSS's use of chemical restraints substantially departs from these generally accepted professional standards of care.

One resident, C.C., received chemical restraints on 60 occasions in a six-month period without any documented assessment to justify the need for such drugs. In another case, W.Q. was chemically restrained 14 times in 35 days, yet there was no documentation that either her psychiatrist or her IDT was aware of how many restraints she was receiving. As discussed above, at section I.A.2.c, psychotropic medications use at LSS is not appropriately assessed by the Psychotropic Review Clinic or by the individual's IDT. This lapse places residents at significant risk of harm.

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[18] In fact, for 34 of those persons, the restraints are classified as "emergency medication." The distinction LSS makes between chemical restraint and emergency medication is not clear, but LSS's use of standing orders for "emergency medication" inappropriately confuses "stat" medications, which should be prescribed in response to a single, unexpected emergency, with "standing," or "pro re nata" ("PRN") medications, which should be prescribed in response to an expected occurrence, e.g., pain medication if an individual expresses discomfort following an invasive medical procedure.

d. LSS Continues the Use of Restraint Even When Proven Ineffective

When a restrictive intervention is effective in preventing or limiting a resident's targeted behavior, the need for the intervention should decrease over time. LSS, however, continues to utilize highly restrictive interventions with numerous residents, often for escalating periods of time, even when the restraint appears to be ineffective.

For example, K.K.H. wears a custom helmet with a "long faceguard" continuously 50 minutes on, and 10 minutes off. However, during the 10 minutes off, K.K.H. must wear a helmet without a faceguard and mitts to prevent PICA. Similarly, U.X., who has a problem with SIB, is subjected to arm splints. U.X. also wears Posey mitts to prevent removal of the splints, and a hard shell helmet with ear protectors and face shield. Another resident, U.V., is restrained 40 minutes of every waking hour, with 20 minutes out of restraint. At night, he is restrained with arm splints until he falls asleep, and continues to be restrained with Posey mitts to prevent scratching his ears. Residents S.H. and T.K. wear jumpsuits to prevent PICA.

Although the facility collects data regarding the use of restraints, it does not appear that the data lead to reconsideration of alternative methods of dealing with the residents' targeted behaviors or modification of residents' behavior programs. Moreover, contrary to generally accepted standards, there is no procedure whereby an increasing number of restrictive interventions trigger a review of a resident's behavioral treatment by the entire treatment team.

We were unable to find any evidence that these individuals' behavioral problems in any way improved as a result of these fundamentally regressive interventions. Notwithstanding the existence of widely-used, indeed generally accepted, behavioral interventions that have had demonstrated success resolving similar behaviors in populations like that of LSS, these LSS residents would appear relegated to spend the rest of their lives encased in barred helmets, arm splints, and hand mitts. While undoubtedly well-intended, LSS's choice of behavioral interventions cannot be readily viewed as humane in effect.

3. Habilitation Treatment and Activity Programming

LSS's residents are entitled to adequate habilitative treatment to ensure safety and facilitate their ability to function freely from restraints. LSS's habilitation treatment

services and activity programming substantially depart from generally accepted professional standards of care. As a result, residents' skills are allowed to deteriorate, and they are denied the opportunity to live in more integrated settings.

Many LSS residents receive little meaningful training. During our visit, we observed a low level of staff interaction with residents. On several occasions during periods of expected activity, we saw numerous residents sitting unengaged in chairs, even though staff were present. When residents are not provided with adequate habilitation treatment programming, not only are they less likely to learn adaptive behaviors, they are more likely to seek attention through maladaptive behaviors, such as aggression and self-injury.[19] Since a lack of meaningful activity often exacerbates behavior problems, the result is an increase in the use of restraints.

The lack of adequate activity programming is due, in part, to inadequate training and supervision provided to direct care staff. Even for those residents whose habilitation plans called for meaningful activities, LSS fails to provide staff with adequate training on how to implement habilitation plans. Separately, many habilitation programs were quite poor. Examples of counter-productive habilitative programs include:

- A "nutrition training session" involving passing a placard picture of a hotdog among residents, who engaged in self-injurious behavior and lacked typical communication skills, and asking them to identify the item. As we observed, one of the residents attempted to eat the cardboard hotdog.

- Attempting for several years to teach H.Q. to tell time by having him set his alarm clock for 15 minutes a day. This exercise is not functional; it is highly unlikely to enable H.Q. to tell time.

LSS's programs and services lack function and relevance and are provided outside the natural context. Consequently, residents fail to acquire skills that will enable them to live safely, free from restraints.

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[19] In this regard, the identified function of nearly all documented problem behaviors at LSS is staff attention.

4. Speech and Communications

If communication skills deteriorate or are not developed, residents are more likely to be unable to convey basic needs and concerns, are more likely to engage in maladaptive behavior as a form of communication, and are more likely to be at risk of bodily injury, unnecessary psychotropic medications, and psychological harm from having no means to express needs and wants. Lack of communication skills also will make it more difficult for staff to recognize and diagnose health issues such as pain. LSS fails to provide its residents with adequate and appropriate communication services. There is an obvious absence of communication assessment strategies that identify communication needs and corresponding supports.

LSS's speech services are insufficient to meet the significant needs of its residents. In particular, the facility fails to provide residents with a needs assessment that addresses the resident's ability to communicate, whether the resident has any swallowing disorders, and whether the resident should receive alternative or augmentative communication devices. The communication plans that LSS provides do not seek to enhance communication skills and safe eating and swallowing practices. Moreover, monitoring of the plans' implementation is not adequate. Further, the absence of information in LSS's plans of care regarding the resident's unique communication abilities, the manner in which the resident communicates his or her needs, and the limitations of his or her ability, constitutes a significant departure from generally accepted standards of care.

These weaknesses appear to derive from a severe shortage of resources to meet communication needs. By LSS's own statistics, 321 of the 344 residents at LSS have been diagnosed with a communication disorder, and 214 of those residents have a severe need for communication services. Yet, only one part-time, masters-level speech professional is contracted to provide services to residents with a communication disorder.

Additionally, LSS fails to provide any augmentative and alternative communication ("AAC") evaluations and services. AAC devices (e.g., communication boards, electronic devices, etc.) are used by individuals who have the capacity to communicate with others, but who have impairments that interfere with their ability to do so verbally. AAC devices enable individuals who otherwise would be unable to do so to explain their medical (e.g., pain, illness symptoms, etc.) or other problems (e.g., abuse, neglect, etc.). AAC devices can be critical to community placement and independent living opportunities. Contrary to

generally accepted professional standards of care, LSS has no policy regarding the provision of an AAC to residents with a need for communication assistance.

This failure to provide adequate communication services causes significant harm to residents. For example, S.E., now 40 years old, has lived at LSS since the age of five. S.E. was hospitalized for several weeks in March 2004 due to a "severe" urinary tract infection that required special cauterization. Upon release from the hospital, S.E. had "dramatic increases in SIB and tissue damage." The IDT opined that the increases in SIB "may be due to pain or discomfort as he cried, moaned, shook as well as episodes of feeling hot to the touch and sweating . . . . He calmed after given pain medication . . . . It became clear he required restraint to prevent further injury caused by his SIB." His BSP was revised to include the use of a helmet and mitt restraints and Atvian three times a day for anxiety. There is no documented evidence of strategies to assist staff in recognizing S.E.'s manner of communicating pain for early detection, or that communication intervention has been developed so S.E. does not have to go to the extreme of causing severe injury to himself to communicate his need for assistance.

D. SERVING RESIDENTS IN THE MOST INTEGRATED SETTING

Texas is failing to serve residents of LSS in the most integrated setting appropriate to their individualized needs, in violation of Title II of the ADA and the regulations promulgated thereunder. One such regulation – the "integration regulation" – provides that "[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d). The preamble to the regulations defines "the most integrated setting" to mean a setting "that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." 28 C.F.R. § 35, App. A at 450.

In construing the anti-discrimination provision contained in Title II of the ADA, the Supreme Court has 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, President Bush, as part of his New Freedom Initiative, has decreed it a major priority for his Administration to remove barriers to equality and to expand opportunities available to Americans living with disabilities. As one step in implementing the New Freedom Initiative, the President, on June 18, 2001, signed Executive Order No. 13217, entitled "Community-Based Alternatives for Individuals with Disabilities." This Order emphasized that unjustified isolation or segregation of qualified individuals with disabilities in institutions is a form of prohibited discrimination and that the United States is committed to community-based alternatives for individuals with disabilities. Exec. Order No. 13217, §§ 1(a)-(c), 66 Fed. Reg. 33155 (June 18, 2001).

As to the residents of LSS, the State of Texas has not taken adequate steps regarding: (1) community placements; (2) assessments; (3) communication of information on community resources to residents, guardians, and family members; and (4) execution of the discharge process. As a consequence, individuals who desire to live in the community, and who reasonably can be accommodated there, are denied the opportunity to live and work in more integrated settings in violation of the State's obligations under Title II of the ADA.

1. Inadequate Community Placements

LSS does not have a systematic transition and discharge placement planning process that actively seeks to place in a more integrated setting individuals who can be accommodated there. During our visit we interacted with a number of remarkably capable individuals. Their presence at LSS provided a strong indication that the State is failing to serve in a more integrated setting individuals who can be reasonably accommodated there. In 2003, only eight individuals were placed in community-based facilities. The following year, that number dropped to 6 individuals. As of March 2005, only two individuals had been placed outside LSS.

2. Inadequate Assessments

Generally accepted standards regarding the transition of persons with developmental disabilities from institutions to the community require that treatment teams carefully evaluate the needs of each individual by taking into account the person's

strengths, limitations, and preferences, and identify services to be provided in the most integrated setting appropriate to the individual's needs. LSS has no comprehensive facility policy by which to guide transitions from the institution to community living arrangements. Without such a roadmap on how to construct an appropriate placement, transition planning is inconsistent and ineffective.

Similarly, successful implementation of community transition depends on the development of a transition plan that sets forth: an action plan identifying the individual's strengths, weaknesses, and preferences; needed individual supports in the community, along with time lines by which specified staff are to develop the supports; a list of all assistive devices being used currently or still needed for placement to occur; a list of activities to be completed before, during, and after transition; and requirements for "follow along" after a placement has occurred.

Contrary to the requirements of the ADA, LSS's interdisciplinary teams appear to endorse the retention of individuals in the institution. The teams do not develop complete analyses of how and where each resident can be appropriately served in the most integrated setting. LSS fails to provide treatment to individuals in the most integrated setting appropriate to their needs, as determined by professional judgment. LSS fails to exercise professional judgment to determine the individual's appropriateness for community-based placement, to determine criteria for discharge, to identify resources necessary to facilitate the placement, and to develop a schedule for instituting the placement.

LSS's interdisciplinary teams assert that LSS is the most integrated setting even for those residents who have communicated their desires for community placement. For example, despite M.H.'s stated goal to live in a home or group home, M.H's program plan states that LSS remains her most integrated setting. M.H. is described as "verbal and able to express her own opinion." However, her representative from the Texas Mental Retardation Authority seeks to have her remain at LSS, while providing no rationale or criteria for discharge. The unsubstantiated conclusion that LSS is her most integrated setting is highly questionable.

II. REMEDIAL MEASURES

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

A. Health Care

1. General Medical Services

The facility should ensure that residents of LSS receive routine, preventative, and emergency medical and dental care consistent with current, generally accepted professional standards. LSS should ensure that residents with health problems are identified, assessed, diagnosed and treated in a timely manner consistent with current, generally accepted standards of care. Specifically, the facility should:

a. Develop and implement strategies to secure and retain adequate numbers of trained nursing staff.

b. Ensure that nursing care plans include individualized proactive interventions; ensure that individuals who are identified as "at risk" or "high risk" are identified, monitored consistent with their risk status, and treated according to generally accepted practices.

c. Develop a system to analyze and monitor the use of "pro re nata" (as-needed) medications on a regular basis.

d. Develop a system to analyze and address medication variances on a regular basis.

e. Develop and implement an adequate system of documentation to ensure timely, accurate, and thorough recording of all medical and nursing care provided to LSS's residents; ensure that menses records, monthly breast examinations, vital signs, and bowel management records are timely entered. Ensure that internal audits and chart reviews are regularly conducted to identify areas of weakness or strength.

f. Check emergency equipment on every shift and document that it is in full working order.

g. Provide competency-based training, consistent with generally accepted professional standards of care, to staff in the areas of: basic emergency response and first aid, infection control procedures, skin care, meal plans, and sanitation of adaptive equipment.

h. Develop a system of pharmacy review to appropriately identify adverse drug interactions and recommend follow-up as needed, including medical and laboratory tests.

i. Provide quality assurance programs, including medical peer review and quality improvement systems, to regularly evaluate the adequacy of medical care.

j. Ensure that comprehensive dental assessments are recorded in the medical record.

2. <u>Occupational and Physical Therapy Services/ Physical and Nutritional Management</u>

The facility should ensure that residents of LSS receive adequate and appropriate assessment and treatment by occupational and physical therapy services consistent with current, generally accepted professional standards of practice. The facility should ensure that there are a sufficient number of adequately trained therapy staff, adequate resources, and quality improvement procedures to ensure adequate therapy services, including physical and nutritional management services, to residents in need. Specifically, the facility should:

a. Develop and implement a system to regularly evaluate and document the status of residents who require therapy services, including baseline data, utilizing generally accepted measurement standards, and status updates at regular intervals.

b. Provide adequate levels of specialized training to members of the Physical Nutritional Management Team to ensure that services are provided on the basis of

current, generally accepted standards of practice.

c. Identify all individuals at LSS who have physical and nutritional management needs and develop and implement treatment interventions to address the needs. Develop meal plans that provide staff clear, individualized instructions regarding necessary supports (e.g., positioning and food texture) to keep individuals safe during mealtimes.

d. Develop and implement a system to monitor, document, and respond to individual triggers, across normal life activities, related to dysphagia; regularly review all dysphagia monitoring data.

e. Develop competency-based training for all LSS staff who assist individuals with dysphagia or choking risks.

3. <u>Psychiatric Services</u>

No resident should receive psychotropic medications without having first been thoroughly evaluated and diagnosed according to current professional standards of care, including sufficient documentation to withstand clinical scrutiny. More particularly, the facility should:

a. Develop standard psychological and psychiatric assessment and interview protocols for reliably reaching a psychiatric diagnosis for individuals with mild and moderate mental retardation and standard protocols for individuals with severe and profound mental retardation. Use these protocols to assess each person upon admission for possible psychiatric disorder(s).

b. Undertake a thorough psychiatric evaluation/work up of all individuals currently residing at LSS, provide a clinically justifiable current diagnosis for each individual, and remove all diagnoses which cannot be clinically justified.

c. As to all residents residing at the facility receiving psychotropic medications, undertake a new psychiatric consultation to ensure that all such medications are appropriate and are specifically matched to current, clinically justifiable diagnoses.

d. Ensure that each psychotropic medication is prescribed in its appropriate therapeutic range.

e. Ensure that an interdisciplinary process is utilized at Psychotropic Review Clinics, and ensure that the following persons attend: the individual, the primary care physician, and members of the interdisciplinary team.

f. If more than one drug is prescribed for the same indication, provide a particularized justification at the mechanism level for the polypharmacy, and eliminate all polypharmacy that cannot be justified at the mechanism level.

g. In all prescriptions and psychiatric consults, specify the marker or target variables for each drug and the expected time line for the effects to be evident. Monitor the use of each such medication against the markers or target variables that have been identified to evaluate its effect. Reassess diagnoses and treatments as appropriate.

h. Ensure that, where psychotropic medications are used, ongoing consideration is given to the potential impact of the individual's other medications, and the impact on other aspects of the individual's health.

i. Develop and implement a system to assess and refer individuals for individual and group therapy, as necessary.

j. Develop and implement a system to evaluate and track the use of pre-medications by outcomes, including injury and cognitive deficiency; alert the psychiatrist when such medications are utilized; and initiate

programs to reduce the use of such medications through de-sensitization programs.

k. Develop and implement a system for collaboration between the psychiatrist and the neurologist to treat residents who have a mental illness and a seizure disorder.

B. Protection from Harm

Incidents involving injury and unusual incidents should be reliably and accurately reported and investigated, with appropriate follow-up. More particularly, LSS should:

1. Ensure that incidents involving injury and unusual incidents are tracked and analyzed to identify root causes.

2. Ensure that analyses are transmitted to the relevant disciplines and direct-care areas for responsive action, and responses are monitored to ensure that appropriate steps are taken.

3. Ensure that assessments are conducted to determine whether root causes have been addressed and, if not, ensure that appropriate feedback is provided to the responsible disciplines and direct-care areas.

4. Ensure that all staff and (to the extent possible) residents are trained adequately on processes for reporting abuse and neglect.

C. Behavior Programs, Restraints, and Habilitation

1. Behavioral Programs

Behavioral data used in forming psychological assessments should be current, accurate and complete; behavioral assessments should be complete and substantiated; treatments should be geared toward improving the individual's quality of life, and all of the foregoing should be implemented according to current professional standards of care, including with documentation sufficient to withstand clinical scrutiny. More particularly, LSS should:

a. Develop standard protocols for efficient, accurate collection of behavioral data, including relevant contextual information.

b. Develop standard psychological assessment and interview protocols. Ensure in these protocols that possible medical, psychiatric, or other motivations for target behaviors are considered.

c. Use these protocols to ensure that functional assessments and findings about behaviors are adequately substantiated, current, and complete. In this regard, ensure that other potential functions have been assessed and excluded.

d. Ensure that behavioral plans are written at a level that can be understood and implemented by direct care staff.

e. Ensure that outcomes of behavioral plans include fundamental objectives, such as reduction in use of medication, enhanced learning opportunities, and greater community integration.

f. Ensure that outcomes are frequently monitored, and that assessments and treatments are reevaluated promptly if target behaviors do not improve.

g. Ensure that the psychologist-to-resident ratio is adequate to support both residents needing behavior programs and the facility's general population.

h. Ensure that psychiatric disorders or conditions that require primary, or adjunctive psychopharmacological treatment, are distinguished from essentially learning-based behavior problems that require behavioral or other interventions. Expressly identify those that have overlap. Provide appropriate, integrated treatment.

i. Ensure that behavior plans reflect an assessment, in a manner that will permit

clinical review, of medical condition(s), psychiatric treatment, and the use and impact of psychotropic drugs.

2. Restraints and Restrictive Controls

Any device or procedure that restricts, limits, or directs a person's freedom of movement (including, but not limited to, mechanical restraints, physical or manual restraints, chemical restraints, or time out procedures) ("Restrictive Controls") should be permissible only as a last resort. More specifically, LSS should:

a. Develop and implement a policy on restraints and restrictive measures that comports with current professional standards.

b. Eliminate use of mechanical restraints from all behavior plans and programs and limit use of mechanical restraints to true emergency situations.

c. Eliminate prone holds in all circumstances.

d. Eliminate "as needed" or "standing orders" for Restrictive Controls.

e. Eliminate use of all other Restrictive Controls except:

(i) when active treatment strategies have been attempted or considered in a clinically justifiable manner and would not protect the person or others from harm;

(ii) other, less intrusive or restrictive methods have been ineffective; and

(iii) as a planned, approved intervention, when a person's behavior poses an immediate risk of harm to self or others.

f. Ensure that an individual in restraint is given appropriate opportunities for toileting, nourishment, and exercise of

restrained limbs, and is released from restraint as soon as he or she does not pose an immediate risk of harm to any person.

g. Convene an interdisciplinary team to review and revise, as appropriate, the behavior support plan of any individual placed in restraints more than three times in any four-week period.

h. Provide ongoing competency-based training for all psychology, supervisory, and direct care staff on treatment and behavioral interventions including the proper use of restraints, and on data collection regarding restraint use.

i. Ensure that only the least restrictive restraint techniques necessary are utilized and that restraints are never used as a substitute for adequate behavioral interventions, as punishment, or for the convenience of staff.

j. Maintain quality assurance oversight to ensure that restraint use is proper and accurately tracked.

3. Habilitation

LSS should provide its residents with adequate habilitation, including but not limited to individualized training, education, and skill acquisition programs developed and implemented to promote the growth, development and independence of each resident, to minimize regression and loss of skills, and to ensure reasonable safety, security, and freedom from undue use of restraint. More specifically, LSS should:

a. Formalize habilitation planning protocols, policies and procedures consistent with generally accepted professional standards of care for use throughout LSS.

b. Provide staff competency-based training on the development of individualized habilitation plans and their implementation.

c. Develop and implement individualized habilitation programming directly matched to each resident's goals, interests, needs, and lifestyle preferences.

d. Monitor and analyze the efficacy of the individualized planning and implementation process. Each individualized plan should have outcome measures that specify action steps and training strategies, and related target dates and responsible staff. Revise programming, as appropriate, based on outcomes.

D. <u>Serving Persons in the Most Integrated Setting Appropriate to Their Individualized Needs</u>

1. Develop and implement comprehensive, formal guidelines, policies, and procedures for transition planning. These should include, at a minimum, target dates, measurable outcomes, training and transition strategies, and responsible staff.

2. Assess the specific characteristics of the most appropriate setting and support needs for each resident of LSS. Assessments (for new admissions) should be done at admission. Periodically update the assessments for individuals who remain at the facility for extended periods of time.

3. If it is determined that a more integrated setting would appropriately meet the individual's needs, promptly develop and implement, with appropriate consent, a transition plan that specifies actions necessary to ensure a 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.

4. Provide adequate education about available community placements to residents and their families or guardians to enable them to make informed choices.

5. Provide adequate staff training and resources to ensure timely and adequate transition planning.

* * *

The collaborative approach that the parties have taken thus far has been productive. We hope to continue working with the State in an amicable and cooperative fashion to resolve our outstanding concerns regarding LSS.

Please note that this findings letter is a public document, and it will be posted on the Civil Rights Division's website. While we will provide a copy of this letter to any individual or entity upon request, as a matter of courtesy, we will not post this letter on the Civil Rights Division's website until 10 calendar days from the date of this letter.

Provided our cooperative relationship continues, we also would be willing to send our expert consultants' evaluations of the facility under separate cover. These reports are not public documents. Although the reports are our expert consultants' work and do not necessarily represent the official conclusions of the Department of Justice, their observations, analyses, and recommendations provide further elaboration of the issues discussed in this letter and offer practical assistance in addressing them.

We are obligated by statute to advise you that, in the unexpected event that we are unable to reach a resolution regarding our concerns, the Attorney General may institute a lawsuit pursuant to CRIPA to correct deficiencies of the kind identified in this letter forty-nine days after appropriate officials have been notified of them. 42 U.S.C. § 1997b(a)(1). We would prefer, however, to resolve this matter by working cooperatively with you, and we are confident that we will be able to do so in this case. The lawyers assigned to this matter will be contacting your attorneys to discuss this matter in further detail. If you have any questions regarding this letter, please call Shanetta Y. Cutlar, Chief of the Civil Rights Division's Special Litigation Section, at 202-514-0195.

Sincerely,

/s/ Wan J. Kim
Wan J. Kim
Assistant Attorney General

cc: The Honorable Greg Abbott
Attorney General
State of Texas

Adelaide Horn
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Texas Department of Aging and Disability Services

Nancy Condon
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Richard B. Roper, III
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Northern District of Texas