



U.S. Department of Justice

Civil Rights Division

*Assistant Attorney General
950 Pennsylvania Avenue, NW - RFK
Washington, DC 20530*

December 1, 2008

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

Re: Statewide CRIPA Investigation of the Texas State
Schools and Centers

Dear Governor Perry:

I write to report the findings¹ of the Civil Rights Division's investigation of conditions at 12 Texas State Schools and Texas State Centers ("the Facilities")² for persons with developmental disabilities, located throughout the state of Texas ("State"), pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997.

¹ After issuing this letter, we were contacted by the State concerning the accuracy of some of the information in Section II: Description of the Facilities. Specifically, the State was concerned about the accuracy in our reporting of the State's ratings and the number of regulatory deficiencies found for some of the facilities. We appreciate the State's diligence and commend the State for bringing this issue to our attention. In response to the State's concerns, in some instances, we have amended the facility description information contained herein. The amendments do not alter any of our findings regarding the facilities as they are described in other sections of the letter. The State separately has been notified of each change.

² The 12 Facilities are: Abilene State School, Austin State School, Brenham State School, Corpus Christi State School, Denton State School, El Paso State Center, Lufkin State School, Mexia State School, Richmond State School, Rio Grande State Center, San Angelo State School, and San Antonio State School.

The Facilities are residential treatment facilities for persons with developmental disabilities that are owned and operated by the Texas Department of Aging and Disability Services ("DADS"). On March 17, 2005, the Department of Justice ("Department") notified you of our intent to conduct a CRIPA investigation of the Lubbock State School ("Lubbock"). We notified you of our intent to conduct a CRIPA investigation of the Denton State School ("Denton") on March 11, 2008. Finally, on August 20, 2008, we notified you that we were opening CRIPA investigations of all the remaining State Facilities for persons with developmental disabilities. 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. We issued our findings regarding Lubbock on December 11, 2006. We write now to advise you of our findings regarding the remaining 12 Facilities.

During the week of May 12, 2008, we conducted an on-site inspection of Denton, the largest of the Facilities, 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. We also reviewed facility policies and procedures, interviewed administrators and staff, and observed residents in a variety of settings, their residences, activity areas, classrooms, workshops, and during meals. Consistent with our commitment to provide technical assistance and conduct a transparent investigation, we conducted an exit conference with Denton staff to convey our preliminary findings. Before, during, and after our site visit, we reviewed medical and other records relating to the care and treatment of Denton residents. We appreciate the cooperativeness, assistance, and professionalism of the Denton administrators and staff throughout the investigation. We also were impressed by the number of staff we observed who appeared genuinely concerned with the well-being of the persons in their care.

On September 9, 2008, we requested several documents related to the organization, census, staffing, risk factors, incidents, restraint use, medical emergencies, medication use, community placement, abuse and neglect investigations, resident mortalities, and treatment planning at the remaining 11 Facilities. In addition, we collected documents related to external surveys and investigations of the Facilities, analyzed statistical data of the Facilities, and reviewed public information released by the State.

The Department was prepared to conduct on-site inspections, with expert consultants, at several of the remaining Facilities. However, in the spirit of cooperation, and with the mutual goal of moving quickly to the implementation of lasting reform, the Department and the State agreed to attempt to resolve the statewide CRIPA investigations in an expedited manner. Specifically, the Department agreed to forego additional on-site inspections of the remaining Facilities at this time and to produce a global assessment of the 12 remaining Facilities, based on systemwide document review, the Department's in-depth investigation of Denton and Lubbock, and further information regarding conditions at the other 12 Facilities. The State has concurred with this approach.

Consistent with our statutory obligations under CRIPA, I now write to advise you formally of the findings of our investigation of the Facilities, the facts supporting them, and the minimum remedial steps that are necessary to remedy the deficiencies set forth below. 42 U.S.C. § 1997b(a). We have concluded that numerous conditions and practices at the Facilities violate the constitutional and federal statutory rights of their residents. In particular, we find that the Facilities fail to provide their residents with adequate: (A) protection from harm; (B) training and associated behavioral and mental health services; (C) health care, including nutritional and physical management; (D) integrated supports and services and planning; and (E) discharge planning and placement in the most integrated setting. See Youngberg v. Romeo, 457 U.S. 307 (1982); Title XIX of the Social Security Act, 42 U.S.C. § 1396; 42 C.F.R. Part 483, Subpart I (Medicaid Program Provisions); Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132 et seq.; 28 C.F.R. § 35.130(d); see also Olmstead v. L.C., 527 U.S. 581 (1999).

I. BACKGROUND

The 12 Facilities provide campus-based direct services and supports to people with developmental disabilities. DADS currently serves approximately 4,595 residents in the 12 residential Facilities.³ The Facilities' residents possess diverse abilities and functional levels and have varying intellectual abilities. The diagnoses of the Facilities' residents with mental retardation range from mild to profound. The Rio Grande State Center includes a 55-person mental health unit. Some of the Facilities have a significant number of

³ There are an additional approximately 285 residents at Lubbock.

juvenile residents who have been placed there following criminal charges, which may present additional security and safety challenges. Some residents require more staffing supports to meet their daily needs, while others are much more independent and capable of meeting their own needs. Many of the residents have swallowing disorders, seizure disorders, ambulation issues, or other health care needs. A significant portion of the Facilities' population has medically complex issues, which require assistance at mealtimes and other frequent monitoring.

Many of the Facilities' residents struggle with maladaptive behaviors, such as self-injurious behavior or aggression. A significant proportion of the Facilities' residents have been diagnosed as having mental illness; and, of those residents with an Axis I disorder diagnosis,⁴ virtually all had been prescribed one or more psychotropic medications.

All the Facilities receive Medicaid funding from U.S. Department of Health and Human Services ("HHS"). For Medicaid purposes, each of the Facilities is certified to care for individuals as an Intermediate Care Facility for the Mentally Retarded ("ICF/MR"). As a condition of receiving Medicaid funds as an ICF/MR, the Centers for Medicare and Medicaid Services ("CMS") requires a regular survey of conditions and investigation of certain incidents reported at participating institutions, including the Facilities. CMS's 2006 and 2007 surveys identified significant care and safety deficiencies at more than two-thirds of the Facilities, including instances of "immediate jeopardy," which placed certain Facilities in danger of losing Medicaid certification and funding.⁵

In the Lubbock investigation, we found that the facility had substantially departed from generally accepted professional

⁴ Pursuant to the American Psychiatric Association's diagnostic criteria manual, Axis I disorders are clinical disorders and/or other conditions that may be a focus of clinical attention. Typically, these clinical disorders include mental illness. Mental retardation and personality disorders are classified as falling under Axis II.

⁵ Immediate jeopardy is a "situation in which immediate corrective action is necessary because the provider's noncompliance with one or more requirements of participation or conditions of participation [in Medicaid] has caused, or is likely to cause, serious injury, harm, impairment, or death to an individual receiving care in a facility." 42 C.F.R. § 442.2.

standards of care in its failure to: protect residents from harm; provide adequate behavioral services; provide freedom from unnecessary or inappropriate restraints; provide adequate habilitation; provide adequate medical care (including psychiatric services, general medical care, pharmacy services, dental care, occupational and physical therapy, and physical and nutritional management); and provide services to qualified individuals with disabilities in the most integrated setting appropriate to their needs. Unfortunately, our current findings indicate that serious problems and deficiencies in care similar to those found at Lubbock currently exist throughout the Facilities.

Corroborating our assessment is the fact that more than 800 employees across all 13 Facilities have been suspended or fired for abusing Facility residents since Fiscal Year 2004. Over 200 of the Facilities' employees reportedly were fired in Fiscal Year 2007 alone for abuse, neglect, or exploitation of residents, and another 200 reportedly were fired for these reasons in Fiscal Year 2006. Further corroborating this assessment is that fact that CMS also found serious deficiencies at multiple Facilities. Although the volume of allegations varies with each Facility, the nature and severity of the allegations are consistently significant. Further, the State's own statistics demonstrate that these problems are systemwide.

As is evident in the following discussion, much of the Facilities' difficulties stem from high staff attrition rates and from staff vacancies, especially for direct care staff and clinicians. Until the Facilities can successfully retain, train, and supervise their staff, they will face enormous difficulties in addressing the identified deficiencies.

II. DESCRIPTION OF THE FACILITIES

A. Abilene State School ("Abilene")

Abilene is located in the City of Abilene, approximately 150 miles west of Fort Worth. This Facility has 662 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or developmental disabilities. As a matter of context, recent CMS surveys corroborate our findings regarding this Facility. The most recent comprehensive CMS inspection of Abilene occurred on April 25, 2008. CMS cited Abilene for 7 deficiencies regarding

federal standards,⁶ including: failure to provide active treatment; failure to provide consistent client training; failure to review and revise individual program plans; failure to provide a clean environment; failure to comply with the Life Safety Code for fire safety; and failure to provide clients' health care services.

B. Austin State School ("Austin")

Austin is located in the City of Austin. It has 474 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or developmental disabilities. As a matter of context, recent State and CMS surveys corroborate our findings regarding this Facility. In 2008, Austin's rating by the State's own Quality Reporting System ("QRS")⁷ was 20 out of 100. The most recent comprehensive CMS inspection of Austin occurred on October 26, 2007. CMS cited Austin for 43 deficiencies regarding federal standards, including, but not limited to: failure to address serious and recurring problems; failure to protect client's rights, including, the right to be free from abuse, neglect and mistreatment; failure to have or to use policies and procedures that prohibit mistreatment, neglect, or abuse of clients; failure to show that all allegations of abuse, neglect, or mistreatment were thoroughly investigated; failure to ensure that drugs were administered in compliance with physician's orders; and failure to provide clients' health care services, prompt treatment, preventative services, and follow-up care. During inspections conducted for the sole purpose of investigating complaints and

⁶ CMS citations are to federal regulations and, while highly probative, they may not necessarily constitute constitutional violations.

⁷ QRS is a DADS system that provides public information to help consumers and guardians evaluate the quality of long term care services at the Facilities and other providers. The rating consists of the sum of two categories of compliance with regulatory standards. Each category has a maximum possible total of 50 points, with points allocated in 10-point increments. The first category reflects the lowest level of compliance resulting from any regulatory investigation of a facility in the preceding six months, and the second the lowest level of compliance in the most recent comprehensive regulatory compliance survey of the facility.

incidents in 2008, Austin had 10 deficiencies cited regarding federal standards.

C. Brenham State School ("Brenham")

Brenham is located south of the City of Brenham, approximately half-way between Austin and Houston. It has 520 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or developmental disabilities. As a matter of context, recent CMS surveys corroborate our findings regarding this Facility. The most recent comprehensive CMS inspection of Brenham occurred on August 8, 2008. CMS cited Brenham for 18 deficiencies regarding federal standards, including, but not limited to: failure to implement active treatment; failure to provide needed client training; failure to review and revise individual program plans; failure to provide and maintain adaptive equipment; failure to meet minimum fire safety requirements; and failure to ensure an effective infection control program. During inspections conducted for the sole purpose of investigating complaints and incidents in 2008, Brenham had two deficiencies cited regarding federal standards.

D. Corpus Christi State School ("Corpus Christi")

Corpus Christi is located in the City of Corpus Christi. It has 432 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or developmental disabilities. Residents range in age from 18 years to 77 years and many individuals require 24-hour nursing care due to severe physical disabilities or medical conditions. As a matter of context, recent CMS surveys corroborate our findings regarding this Facility. A comprehensive CMS inspection of Corpus Christi occurred on September 21, 2007. CMS cited Corpus Christi for 19 deficiencies regarding federal standards, including, but not limited to: failure to develop measurable objectives; failure to provide health services; failure to secure drugs and biologicals; failure to ensure unlicensed staff did not administer medications; and failure to meet Life Safety Code standards.

E. Denton

Denton is located in the City of Denton, approximately thirty miles north of Dallas. This Facility has 716 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or

developmental disabilities. A large number of the residents are medically fragile and require constant medical care. As a matter of context, recent State and CMS surveys corroborate our findings regarding this Facility. In 2008, Denton's QRS rating was 20 out of 100. The most recent comprehensive CMS inspection of Denton occurred on April 4, 2008. CMS cited Denton for 25 deficiencies regarding federal standards, including, but not limited to: failure to protect client's rights, including the right to be free from abuse, neglect and mistreatment; failure to have or to use policies and procedures that prohibit mistreatment, neglect, or abuse of clients; failure to show that all allegations of abuse, neglect, or mistreatment were thoroughly investigated; and failure to provide clients' health care services, prompt treatment, preventative services, and follow-up care. During inspections conducted for the sole purpose of investigating complaints and incidents in 2008, Denton had 16 deficiencies cited regarding federal standards.

F. El Paso State Center ("El Paso")

El Paso is located in the City of El Paso. This Facility has 155 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or developmental disabilities. As a matter of context, recent CMS surveys corroborate our findings regarding this Facility. In 2008, El Paso's QRS rating was 90 out of 100. The most recent comprehensive CMS inspection of El Paso occurred on June 19, 2008. CMS cited El Paso for five deficiencies regarding federal standards, including, but not limited to: failure to provide health care services; failure to provide and maintain adaptive equipment; and failure to ensure a well-balanced, modified diet.

G. Lufkin State School ("Lufkin")

Lufkin is located in the City of Lufkin, in East Texas. It has 486 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or developmental disabilities. Lufkin residents range in age from 14 to 90 years old, approximately one-half of the residents require mobility assistance, some residents require 24-hour nursing care due to medical conditions, while others require intensive intervention to address behavioral challenges. As a matter of context, recent State and CMS surveys corroborate our findings regarding this Facility. In 2008, Lufkin's QRS rating was 50 out of 100. The most recent comprehensive CMS inspection of Lufkin occurred on April 24, 2008. CMS cited Lufkin for 24 deficiencies regarding federal standards,

including, but not limited to: failure to ensure that clients were free from unnecessary restraints and received active treatment; failure to have sufficient direct care staff to meet the needs of clients; failure to identify the clients' skill deficits and maladaptive behaviors; failure to remove outdated drugs from stocks; failure to provide a clean environment; and failure to meet minimum fire safety requirements. During inspections conducted for the sole purpose of investigating complaints and incidents in 2008, Lufkin had 10 deficiencies cited regarding federal standards.

H. Mexia State School ("Mexia")

Mexia is located west of the City of Mexia, in East Texas. It has 616 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or developmental disabilities. Mexia also provides services on a statewide basis to both juvenile and adult offenders with mental retardation in two Specialized Treatment Units. The Units also serve individuals with severe behavioral and/or emotional problems from other State Schools; "Developmentally Disabled Delinquents" committed under Chapter 55 of the Texas Family Code; and adult clients admitted under Chapter 46.02 of the Texas Criminal Code who have been determined "not manifestly dangerous." As a matter of context, recent State and CMS surveys corroborate our findings regarding this Facility. In 2008, Mexia's QRS rating was 50 out of 100. The most recent comprehensive CMS inspection of Mexia occurred on May 9, 2008. CMS cited Mexia for 37 deficiencies regarding federal standards, including, but not limited to: failure to address serious and recurring problems; failure to protect client's rights, including, the right to be free from abuse, neglect and mistreatment; failure to have or to use policies and procedures that prohibit mistreatment, neglect, or abuse of clients; failure to protect clients from abuse during investigations; failure to have sufficient direct care staff to meet the needs of clients; and failure to properly educate staff in implementing the individual program plans. During inspections conducted for the sole purpose of investigating complaints and incidents in 2008, Mexia had two deficiencies cited regarding federal standards.

I. Richmond State School ("Richmond")

Richmond is located in the City of Richmond, which is in the greater Houston metropolitan area. This Facility has 664 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or developmental disabilities. As a matter of context, recent CMS

surveys corroborate our findings regarding this Facility. The most recent comprehensive CMS inspection of Richmond occurred on January 12, 2008. CMS cited Richmond for 36 deficiencies regarding federal standards, including, but not limited to: failure to ensure clients' rights were protected, including, the right to be free from abuse, neglect and mistreatment; failure to ensure that clients were free from unnecessary restraints and received active treatment; failure to have sufficient direct care staff to meet the needs of clients; failure to protect clients from abuse during investigations; failure to provide initial and ongoing staff training; failure to show that all allegations of abuse, neglect, or mistreatment were thoroughly investigated; and failure to provide clients' health care services, prompt treatment, preventative services, and follow-up care.

J. Rio Grande State Center ("Rio Grande")

Rio Grande is located in the City of Harlingen, in the Rio Grande Valley. It has 77 residential beds that are ICF/MR certified for adults diagnosed with mental retardation or developmental disabilities and 55 in-patient beds (27 certified by Medicare) accredited by the Joint Commission for Accreditation of Healthcare Organizations for adults diagnosed with mental illness. Rio Grande is also the only Texas state facility to offer both a mental health and a mental retardation program. As a matter of context, recent CMS surveys corroborate our findings regarding this Facility. The most recent comprehensive CMS inspection of Rio Grande occurred on November 29, 2007. CMS cited Rio Grande for ten deficiencies regarding federal standards, including, but not limited to: failure to ensure client's rights were protected, including, the right to be free from abuse, neglect and mistreatment; failure to secure nursing services to meet the needs of clients; failure to show that all allegations of abuse, neglect, or mistreatment were thoroughly investigated; and failure to ensure that all allegations of mistreatment, neglect, or abuse were reported. During inspections conducted for the sole purpose of investigating complaints and incidents in 2008, Rio Grande had one deficiency cited regarding federal standards.

K. San Angelo State School ("San Angelo")

San Angelo is located in the City of San Angelo, in central Texas. It has 375 beds for temporary respite admissions, emergency services, and long term placements for individuals ranging in age from 11 to 91, each having a primary diagnosis of mental retardation. As a matter of context, recent State and CMS

surveys corroborate our findings regarding this Facility. In 2008, San Angelo's QRS rating was 50 out of 100. The most recent comprehensive CMS inspection of San Angelo occurred on March 7, 2008. CMS cited San Angelo for 15 deficiencies regarding federal standards, including, but not limited to: failure to notify client's family or guardian of significant issues; failure to provide measurable objectives; failure to review and update functional assessments; failure to provide health care services; failure to ensure drugs were administered in compliance with physician's order; and failure to provide a clean environment. During inspections conducted for the sole purpose of investigating complaints and incidents in 2008, San Angelo had one such deficiency cited regarding federal standards.

L. San Antonio State School ("San Antonio")

San Antonio is located in the City of San Antonio area. It has 339 beds for temporary respite admissions, emergency services, and long term placements for individuals with mental retardation or developmental disabilities. As a matter of context, recent CMS surveys corroborate our findings regarding this Facility. The most recent comprehensive CMS inspection of San Antonio occurred on September 14, 2007. CMS cited San Antonio for 27 deficiencies regarding federal standards, including, but not limited to: failure to implement active treatment; failure to provide and maintain adaptive equipment; and failure to provide a clean environment. During inspections conducted for the sole purpose of investigating complaints and incidents, San Antonio had five deficiencies cited in 2007 and no deficiencies cited regarding federal standards in 2008.

III. 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 the Facilities substantially depart from generally accepted professional standards of care in that they fail to: (1) provide adequate health care (including nursing services, psychiatric services, general medical care, 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. While specific findings vary among the Facilities, we find that there are systemic deficiencies throughout the Facilities in the delineated areas.

A. PROTECTION FROM HARM

The Supreme Court has established that persons with developmental disabilities who reside in state institutions have a "constitutionally protected liberty interest in safety." Youngberg v. Romeo, 457 U.S. at 318. The Court held that the state "has the unquestioned duty to provide reasonable safety for residents" within the institution. Id. at 324. However, the Facilities fail to provide basic oversight of resident care and treatment critical to ensuring the reasonable safety of their residents. The Facilities also fail to identify risks to prevent foreseeable harm to their residents or respond appropriately once harm to a resident has occurred. Consequently, Facility residents have suffered significant injuries from inadequate supervision, neglect, and possible abuse, and improper use of restraints as a result of inadequate oversight and deficient risk and incident management practices.

As noted above, more than 800 state employees across the Facilities reportedly have been suspended or fired for abusing facility residents since Fiscal Year 2004. Further, 239 employees of the Facilities were fired in Fiscal Year 2007 for abuse, neglect, or exploitation of residents of the Facilities, and 200 employees were fired for these reasons in Fiscal Year 2006. State records indicate that there were 450 confirmed incidents of abuse or neglect in the Facilities in Fiscal Year 2007. In July, August, and September of 2008, the Facilities

opened at least 501⁸ investigations into alleged incidents of abuse, neglect, or mistreatment. As mentioned previously, CMS has cited many of the Facilities in the past year for failing to keep residents free from abuse, neglect and mistreatment.

Illustrative of the complexity of the Facilities' problems related to detecting, reporting, and investigating abuse is a reported incident at one Facility from February 2008. A 17-year-old female resident with mild mental retardation told a staff person that she was raped by a male staff member who had been assigned to supervise her one-to-one and who threatened to hurt her if she told anyone about the sexual assault. Another staff reportedly had entered the alleged victim's room that night and observed the male staff kneeling next to the bed with both hands on the alleged victim's knees and leaning forward as if to kiss her. That staff did not report the incident until two days later. Both staff reportedly were suspended the next day, and the sheriff's office was notified the day after that. Although the facility physician ordered a rape kit and other tests for sexually transmitted diseases to be completed, he noted that, because of the time lapse of two to three days, there would likely not be evidence of sexual activity. The results of those tests were negative. The State substantiated neglect by the observer who failed to immediately report the incident, but made "inconclusive" findings as to the allegation of sexual abuse.

1. Incidents and Injuries

We found that many of the Facilities' risk management practices fail to identify residents' risks and fail to implement preventive strategies necessary to keep residents free from harm and risk of harm. Facility residents face a myriad of physical, mental, and behavioral challenges that increase their susceptibility to self injury, injury or abuse from others, or complications associated with medical, mental health or behavioral conditions. Moreover, a significant number of Facility residents are medically fragile, non-verbal or require assistive devices to communicate, or are non-ambulatory. Therefore, many Facility residents are incapable of protecting themselves from harm or reporting incidents of abuse or neglect.

⁸ Because our September 9, 2008 document request focused only on the 12 Facilities included in the investigation opened on August 20, 2008, we do not have statistics from Denton for the July through September 2008 time period. As such, the actual number of incidents of abuse, neglect, and mistreatment alleged during this time period at all the Facilities is higher than 501.

Identifying and monitoring risk to eliminate harm, where possible, before it occurs is essential if the Facilities are to provide a safe living environment for their residents.

Due to the nursing and direct care staffing shortages and high staff turnover rates at many of the Facilities, the Facilities cannot adequately identify risks and ensure residents' safety. We found that the frequency and severity of critical incidents at the Facilities are disturbingly high and often directly related to insufficient staffing. The Facilities must ensure adequate staffing is available for all shifts if they are to provide residents adequate protection from harm or risk of harm.

a. Pica⁹

The Facilities' staff has failed on several occasions to identify and monitor residents after serious pica incidents. While it is unclear if some of the Facilities even track pica incidents, we documented a very high number of pica incidents, with some individuals engaging in repeated, unchecked pica behavior. One Facility documented 151 cases of pica in 2007, with some individuals involved in 10 to 20 occurrences. Further, our consultants' record review identified additional cases of pica that were not included in these statistics, meaning actual occurrences were higher than reported. We found that two residents had ingested latex gloves, one resident on three occasions, another resident had ingested plastic wrap, while another ingested a checker. We also found two cases of individuals ingesting Swiss Army knives.

Surprisingly, staff often do not witness these pica incidents, and discover the incidents only after the resident experienced health complications such as abdominal pain or after finding the object following a resident's bowel movement or vomiting. Indeed, one Facility only discovered the latest pica incident of the resident who repeatedly had ingested latex gloves only after a glove had calcified in the resident's stomach and required surgical removal. None of these individuals, including the resident who had repeatedly ingested the latex gloves, had a pica diagnosis in their medical charts or behavioral plans, nor were there any notes suggesting that these residents would be monitored for pica after these incidents. In addition to failing

⁹ Pica is the craving or ingestion of non-food items. The digesting of non-food items exposes the individual to a substantial risk of choking and dying.

to adequately develop individualized responses to individuals experiencing pica problems, the Facilities lack a uniform response to safeguarding items likely to be ingested, such as latex gloves.

b. Choking Risks

Many Facility residents are at increased risk for choking. Not only did we uncover several instances in which staff failed to carefully monitor residents at risk for choking, but we also found instances where staff failed to respond appropriately once they discovered an apparent choking episode.

c. Falls

Many other Facility residents suffer significant preventable injuries resulting from seizures and falls. We also found that a significant number of residents' injuries are discovered as opposed to witnessed by staff, strongly suggesting that residents are being neglected. Moreover, we found that the Facilities were not referring residents to physicians in a timely manner following injuries, which thereby needlessly prolonged residents' pain and suffering. Many Facility residents have sustained serious injuries from falls, and yet, are not identified by the Facilities as being at risk of falling. In fact, some of the Facilities do not regularly maintain a list of residents at risk for falls, suggesting that these Facilities do not currently identify individuals at risk for falls and do not implement preventative measures to prevent falls in residents who have fallen repeatedly.

For example, at one Facility, despite more than a dozen falls requiring medical attention, the Qualified Mental Retardation Professional ("QMRP") responsible for coordinating care for one resident reportedly failed to alert the resident's interdisciplinary team ("IDT") about the pattern of falls so that preventive measures could be developed to prevent future harm to the resident.

At another Facility, staff did not report H.H.'s¹⁰ fall until the next morning despite the fact that she suffered a fracture so severe that she subsequently was kept in the

¹⁰ To protect individuals' privacy, they are identified here through coded initials. We will separately give the State a schedule identifying individuals referenced here and the Facility where they reside.

infirmary for nearly two months. Yet another resident of this Facility, P.B., died in June 2007 from blunt force trauma to the head as a result of a fall. P.B. had a history of seizures, and his autopsy specifies that he may have fallen accidentally during a seizure. Given the severity of the fall and P.B.'s injury, however, it is also possible that a fall could have triggered a seizure. P.B. suffered numerous other falls in the year prior to his death, and two of these falls involved tripping and/or pushing by others. Despite this history, the Facility did not specifically identify P.B. as an individual at risk for falls.

2. Restraints

Restraints are to serve only as an immediate protection from imminent harm. Minimally accepted standards dictate that restraints be employed only in the face of imminent risk of harm, when less restrictive interventions have proven unsuccessful and never as a punishment. Further, restraints are to be administered in a hierarchal fashion graduating, only as necessary, from lesser to more restrictive measures. Individuals are to be released as soon as they have gained control and the imminent risk of harm is no longer present. In short, individuals are to be free from restraint except where an immediate and critical threat of harm is present.

Community and institutional healthcare providers have made deliberate strides in reducing and eliminating restraint use. The Facilities' administrators have also expressed a desire to reduce restraint practices and these intentions are well documented. Yet the Facilities are far from realizing minimally accepted standards.

The use of restraints is prevalent at many of the Facilities. From January through September 2008, a total of 10,143 restraints were applied to 751 Facility residents.¹¹ Despite intentions of reduction, restraint use actually increased at some of the Facilities in the past few years.

The methods of restraining individuals are equally disconcerting. The types of restraints include, but are not limited to, psychotropic medications; physical holds; and mechanical restraints including straight jackets; placements on a restraint board; leather straps attached to the wrists, ankles, trunk; face guards; helmets; and mittens. Mechanical restraints

¹¹ These totals include statistics from Denton for the period of January through April 2008 only.

are generally regarded as the most intrusive and restrictive type of restraint and are, with increasing frequency, forbidden by a growing number of providers. Despite the healthcare community's less frequent and decreasing use of these devices, some of the Facilities use them liberally such that mechanical restraints account for a very high percentage of all restraints.

Further, although restraints may be necessary in crisis situations, their misuse can lead to great harm. In January 2007, a teenage resident of one Facility died while being held in six-point restraints. Three staff involved in his care were reportedly terminated after the incident. In July 2007, at the same Facility, a resident being restrained reportedly suffered two black eyes, abrasions on his back, a large bruise on the center of his chest, swelling and bruising to his right elbow, and scratches to his face and arms.

In April 2007, at another Facility, staff reportedly broke a resident's shin bone as they slammed the resident to the ground during a restraint. Reportedly, a staff member asked the resident what he wanted to eat, and, when the resident did not answer, the staff member placed his hand on the resident's shoulder. The resident then allegedly became aggressive, and two staff members restrained him, with one staff member holding the resident's legs. Upon his release, the resident complained of leg pain. Although a nurse examined the resident and noticed his knee was swollen and warm, a doctor did not see him and order x-rays to diagnose the fracture until the next day.

The use of straight jackets, in particular, does not comport with generally accepted professional standards. Yet, we found that restraint jackets are a formal part of some Facility residents' behavioral plans. In one instance in spring 2008, a resident of one of the Facilities suffered a serious injury when restrained in a straight jacket by an insufficient number of staff. All of the Facilities should cease the use of straight jackets immediately.

The administrative review of restraints is equally problematic, as the Facilities often conduct restraint debriefings on emergency restraints alone, which account for only one to five percent of all restraints. Restraint debriefings are used as an opportunity to review the circumstances surrounding the need and use for restraint and determine what, if any, prevention measures may be tried to avoid future restraint use. Debriefings are fundamental to restraint reduction efforts. Failing to conduct thorough restraint debriefings renders any reduction effort virtually meaningless.

Finally, a fundamental consideration when reviewing restraints is determining whether restraints actually prevented serious harm to individuals. Restraints are used for protection and should never result in harm to the resident. Tragically, as indicated above, we found evidence that supports the contrary finding: restraints have been the cause of, and not the protection from injury.

3. Abuse and Neglect Reporting

Inadequate investigations make it difficult to identify, develop, and implement corrective measures to eliminate preventable risks to residents. Some Facility investigations are reported, reviewed, and openly discussed in team management meetings. The discussion of allegations and investigations in open meetings deviates from current professional standards. Information related to any Facility investigation or complaint of alleged abuse and neglect should be shared with only those administrators or care staff who are essential to conducting and completing the investigation. Anything short of this compromises the integrity of the investigation and creates a significant risk of harm to residents. In particular, staff and residents may be unwilling to report incidents of abuse or neglect if they perceive that investigations are not sufficiently confidential. Also, the lack of confidentiality increases staff and residents' risk of reprisal by disgruntled persons when investigation facts are widely known across a Facility. In a departure from generally accepted professional standards, some of the Facilities provide a wide range of employees access to the names of alleged perpetrators, witness' names, and the nature of allegations or investigations. The Facilities must cease the practice of discussing investigations in any meeting not comprised solely of staff essential to the investigatory process to ensure the integrity of the reporting and investigative processes.

B. HEALTH CARE

1. Medical Services

Generally accepted professional standards for the provision of medical care in an institutional setting serving individuals with developmental disabilities require adequate identification, treatment, and monitoring of medical needs. The Facilities need a formal process that addresses: (1) early identification of changes in health status; (2) prompt evaluation to determine the cause; (3) timely initiation of appropriate interventions; and (4) ongoing monitoring to prevent future recurrence.

The mortality rate for some of the Facilities raises serious concerns regarding the quality of care that Facility residents receive. In recent years, one of the Facilities averaged two resident deaths per month. From September 2007 through September 2008, at least 114 Facility residents died. We were especially troubled that at least 53 of the resident deaths during that time period related to aspiration, pneumonia, respiratory failure, sepsis, bowel obstruction, or failure to thrive.¹² Generally, these are preventable conditions that are often the result of lapses in care or a failure to put medical interventions in place in a timely manner.

Although we have encountered many dedicated medical professionals in the State system, the lack of qualified staff render it nearly impossible for staff to focus on preventive care and management of identified risk factors, rather than simply addressing acute medical problems. The physicians and nurse practitioners at the Facilities typically have very large caseloads. Staffing deficiencies also unnecessarily increase the workload of the nurses and other health care staff. As a result, the health care at many of the Facilities is more reactive than proactive, where the residents, especially those with complex and high-risk conditions, do not receive routine adequate preventive health care.

As detailed further below, in an institutional setting where many individuals have complex medical needs, the failure to provide appropriate proactive care renders residents at increased risk of developing acute, but preventable conditions.

a. Nursing Services

The Facilities' reactive approach is apparent in nursing care. Too often, nurses only respond to known or apparent health problems when they reach acute status, rather than providing timely interventions to prevent or mitigate the occurrence of acute problems. It is clear that staffing shortages have greatly

Inadequate recruitment and poor retention, due in part to inadequate training, have been major issues for nursing at most

systemwide mechanism with which to analyze the specific needs of each unit and determine the number and skill set of nursing staff

¹² As the investigations were initiated at different times, these totals include statistics from Denton for the period of June through October 2008 only.

that each unit requires. Instead, nursing staff seem to be assigned to particular units based upon their schedules and availability, without serious regard to the residents' needs. As a result, nursing staff fail to: (1) respond in a timely manner to changes in residents' medical status; (2) participate actively in the treatment team process by providing feedback on residents' responses to medication and behavioral interventions, on a consistent and ongoing basis; and (3) implement adequate infection control procedures. These deficiencies expose Facility

Generally accepted professional standards call for nurses to monitor an individual's health status to detect changes in an individual's condition in a timely manner. This basic nursing practice is largely absent from many Facility resident records. Our review of individual records reflected 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. Recommendations in nursing care plans fail to specify the signs and symptoms that must be monitored. Moreover, nursing care plans for individuals at high risk do not identify individualized interventions related to identified risk factors. We found other residents' care plans that were significantly outdated or ignored major health issues altogether.

For instance, in one Facility, resident N.H. had two choking episodes, one in May 2007 and the other in July 2007. Despite these incidents, her record in 2008 indicated that she had not had a nursing problem since March 9, 2004. N.H. had a modified barium swallow (a swallowing test) following her second choking episode. As a result of this test, the texture of her meals was changed to pureed, and she was weighed bi-weekly due to unexplained weight loss in June 2007. Her nursing care plan was last reviewed in September 2007. In late April 2008, she vomited material resembling coffee grounds, indicating possible gastrointestinal (GI) bleeding. However, none of these issues were identified in her current nursing care plan. At the same Facility, resident L.I. had five hospitalizations for weight loss, multiple episodes of pneumonia, and abdominal distension. However, none of these issues was addressed in his nursing care plan.

In another Facility, a nurse apparently broke a resident's arm during a skin examination in February 2007. Although the resident complained of pain in her arm as the nurse pulled on the arm to examine her skin, the nurse did not stop pulling on the resident's arm. The resident continued to complain of pain for

the next two days, after which, she was taken to the hospital, where her broken arm was diagnosed.

At a third Facility, in April 2007, a 49-year-old resident with a history of congenital intestinal malrotation (a birth defect involving malformation of the intestinal tract) and intestinal adhesions died of an apparent ruptured intestine and possible bowel obstruction. The resident reportedly complained of a stomach ache at 12:30 a.m. A nurse examined him and determined that he did not have any abdominal tenderness, but she noted hypoactive or hyperactive bowel sounds (the records conflict). She gave the resident crackers and returned him to his room. About five and a half hours later, the resident reportedly again complained of stomach pain, this time also vomiting undigested hot dogs and brown fluids. The nurse then notified the doctor, who directed that the resident be transferred to the local emergency room for evaluation. While awaiting facility transport to the local emergency room, the resident had a possible seizure and became non-responsive. By the time he arrived at the hospital, the resident required life support. He reportedly died at 10:30 p.m. Although the nurse was attentive to the resident, the Facility failed to implement adequate nursing protocols regarding the appropriate interventions for a person with a significant history of bowel obstruction.

Furthermore, there is often inadequate collaboration and coordination between nursing and the various health care disciplines. Separate disciplines often fail to work together well, which leads to fragmented health care activity. To compound this problem, documentation often failed to reveal clearly the resident's health status. Recommendations from medical and other staff were difficult to track, and charts often lacked notations indicating the resolution of health issues.

For example, while a chart from one Facility indicated that medical staff recommended a surgical consult for an individual with a rubber glove in his stomach, it was impossible to discern through the records whether such a consultation occurred and how medical professionals resolved the issue. At another Facility, the medical staff reportedly did not inform direct care staff of the reduction in seizure medications for multiple residents, nor train direct care staff to observe possible side effects of medication reductions for these residents. In fact, one direct care staff reported that the Facility had no formal system of informing the staff of medication changes. If this is correct, it represents a substantial departure from generally accepted professional standards of care. Moreover, although Facility

administrators stated that medication changes should have been documented in the staff logbook, no such documentation was apparent.

The identified inadequacies have broad implications for Facility residents. Throughout the Facilities, there is a large percentage of medically fragile residents who are at risk for, among other things, bowel impaction and obstructions, pneumonia and aspiration pneumonia, Gastroesophageal Reflux Disease, seizures, and fractures due to osteoporosis. From January to September 2008, residents were hospitalized on at least 1,409¹³ occasions, with many of these hospitalizations being for preventable conditions.

Bowel impaction and bowel obstructions are preventable conditions that can lead to discomfort, perforations, and even death, if left unaddressed. Generally accepted practice dictates that care givers must be vigilant and take extra steps to prevent impactions and obstructions, especially among persons with developmental disabilities who are non-ambulatory and persons receiving psychotropic medications, such as many of the Facilities' residents. We found various incidents where residents developed bowel obstructions, some of which led to hospitalization and even death, as noted above.

Aspiration pneumonia is typically a preventable condition that results from the accumulation of foreign materials (usually food, liquid, or vomit) in the lungs. Almost 20 percent of the hospitalizations were for respiratory issues such as pneumonia, many identified as aspiration pneumonia. This calls into question whether the Facilities are adequately identifying and treating all those residents at risk of aspiration or choking. For example, a resident of one Facility, T.H., was hospitalized three times in a one year for a range of diagnoses, including aspiration pneumonia. L.I., a resident of the same Facility, was hospitalized in December 2006 for aspiration pneumonia, following a long history of gastrointestinal problems.

At another Facility, a registered nurse reportedly told surveyors in spring 2007 that, although 16 residents who had been identified as being at high risk for aspiration pneumonia had individualized nursing care plans, the Facility used a generic aspiration pneumonia nursing care plan for other at-risk

¹³ As the investigations were initiated at different times, this total includes statistics from Denton for January through April 2008 only.

residents. This is a substantial departure from generally accepted professional standards of care. Further, as of the survey, a plan to have licenced vocational nurses perform weekly breath sounds, to detect possible aspiration, reportedly had not been implemented.

Generally accepted professional standards require adequate infection control. The components of an adequate infection control program fall into two categories: surveillance and reporting; and control and prevention. Surveillance and reporting include data collection, tabulation, and analysis on both the population of the facility and its employees. Facility personnel should be monitored and data analyzed for possible exposure to, or as the source of communicable and infectious diseases. The environment itself must be monitored as a source of potential infection hazards, especially during outbreaks of infections.

Infection control at the Facilities is deficient. Although the Facilities report the number and types of infections, there is no set protocol in place for identifying areas for potential problems. Proper infection control is particularly important in light of the fact that methicillin-resistant staphylococcus aureus ("MRSA")¹⁴ infections are becoming more common throughout institutions.

b. Physical and Nutritional Management

The Facilities typically do not provide physical and nutritional management care consistent with generally accepted professional standards, and Facility residents with dysphagia (swallowing difficulty) and those at risk of aspiration are not provided adequate assessments or interventions to address these conditions. Our consultant's review of one Facility uncovered cases where residents lost as much as ten percent of their body weight with little or no follow up. To provide residents with adequate treatment, the Facilities must have a screening process

¹⁴ MRSA is a bacteria resistant to certain antibiotics, including methicillin, oxacillin, penicillin, and amoxicillin. See Centers for Disease Control and Prevention, at http://www.cdc.gov/ncidod/dhqp/ar_mrsa_ca_public.html. 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.

that identifies those who may have nutritional management issues and must refer those individuals for a more comprehensive assessment. Also, the assessment should assist staff in managing the resident's weight and addressing obstacles that may prevent the resident from stabilizing his weight. The absence of this process has grave consequences, which is evidenced by the fact that a significant number of residents are hospitalized due to nutritional management issues.

The high number of choking incidents demonstrates that many of the Facilities do not adequately monitor residents with dysphagia or who have difficulty swallowing. Many Facility residents have medical conditions or are prescribed medications that compromise their ability to swallow and digest food and beverages. Our review revealed a very high number of choking incidents at many of the Facilities, with many residents involved in multiple choking incidents. Despite these findings, at some Facilities we found no evidence that systematic comprehensive evaluations of residents' physical and nutritional management care plans are conducted following major choking incidents.

For instance, at one Facility, in August 2007, resident D.F. began choking while eating dinner. D.F. has been prescribed several medications, including lithium and valium, which can cause dry mouth, and has experienced three choking episodes in the prior year. Despite this history, it appears that D.F. is not being monitored carefully, putting her at risk of serious harm. Another resident of the same Facility, T.I., had multiple choking episodes, and a history of unexplained weight loss. There was no nutritional evaluation in his records, nor did his health record explain the reason for the rapid weight loss or address his choking episodes.

Furthermore, even residents identified as at risk often do not receive the appropriate treatment because many direct care staff either are unaware of the resident's program or received inadequate training on the steps necessary to ensure that the resident is treated effectively. From the observations of our consultants and reports of surveyors, it is clear that, throughout the Facilities, a high percentage of direct care staff working with high risk residents are unfamiliar with the residents. The meal cards used to identify the necessary supports for each resident while dining are too superficial to assist staff working with residents they do not know. Many direct care staff have little knowledge or appreciation of the critical importance of meal textures, how the residents should be positioned during meal times or how to identify and document

indicators of possible aspiration, including coughing, wheezing, watery eyes, and food refusal.

For instance, at one Facility, a resident's meal card required fluids to be thickened to a honey consistency. Although the resident's liquids were thickened as required, surveyors observed that the resident began to cough as he was drinking. A direct care staff then approached the resident and patted his back while giving him unthickened water, saying, "he does better without that [thickener]." This statement suggests that there are times when the resident's meal orders are not implemented, which places the resident at great risk of choking and aspiration.

Many of the choking incidents involved residents stealing food of the wrong texture. Of 19 choking incidents reviewed at one Facility, six resulted from a resident obtaining food not intended for them. For instance, S.I., a resident of one Facility, choked in June 2008 after stealing a muffin from the kitchen, and also choked again on March 11, 2008 after "borrowing" food from a neighbor whose food texture was different from that prescribed for him. At another Facility, in August 2007, a resident who was on a special diet of ground foods choked on an apple. The resident required two Heimlich maneuvers and was taken to a hospital as a result. It is unclear whether the resident took, or was mistakenly given, the apple. In any event, the fact that residents are able to obtain the wrong food reflects that the Facilities do not have a sufficient number of staff to monitor residents appropriately.

The Facilities must take more of a proactive, cooperative, collaborative, systemic team approach to addressing nutritional and physical support issues to ensure compliance with generally accepted professional standards. This approach must do more to screen residents and focus on familiarizing direct care staff with each resident's physical and nutritional management plans. Otherwise, the risk of aspiration pneumonia and other gastrointestinal problems and hospitalizations will remain unnecessarily high for certain Facility residents.

c. General Clinical Care

Generally, once medical staff at the Facilities identify an acute change in health status, staff provide timely interventions and appropriate documentation about the individual. Nevertheless, the Facilities lack certain critical components of a systemic health care. We found that some medically fragile residents were not transferred to outside hospitals as

appropriate when their medical needs escalated such that Facility infirmaries were not equipped to provide adequate care. We also found that the Facilities do not consistently check emergency equipment to ensure it is in working order. Some Facilities are lacking in quality management and utilization management committees, led by medical professionals, to assess data on medical services, as well as systems to identify medical trends and outcomes. The lack of medical leadership unquestionably affects the Facilities' ability to provide adequate general clinical care and contributes to the breakdown in communication among Facility professionals. Further, several key medical positions are vacant at various Facilities.

In addition, we found records indicating that direct care and nursing staff do not consistently inform medical staff when injuries to residents occur. When staff delay notifying physicians of injuries, residents fail to receive necessary acute care in a timely manner, which potentially exacerbates their condition and forces residents to suffer needlessly.

For example, resident, H.H., noted above, was in a Facility infirmary for approximately two months as a result of multiple fractures she sustained on March 16, 2008. Although the nurse on the evening of March 16, 2008 noted that H.H. exhibited a pained expression and grimaced when she moved her leg, the medical chart does not mention any incident. No report could be located related to this serious incident, but nursing notes from the following morning indicate that H.H. was "reported to have slid out of sling during transfer to bed yesterday at about 1330. No injuries noted at that time." Implementation of instructions from physicians also has been problematic. Another Facility, in the spring of 2007, reportedly failed to carry out physician orders for tests regarding one resident's foot wound, another resident's medication toxicology levels, and a third resident's white blood count.

The problems surrounding the lack of accurate communication between physicians and other staff extend beyond the treatment of injuries. We found numerous examples where episodes of pica resulted in medical treatment, but the psychology staff seemed unaware of these incidents. Physicians, psychiatrists, psychologists, and other treatment team members must be adequately informed of injuries and incidents in order to take action to analyze a problem or to provide staff with additional training.

e. Pharmacy Services

Some of the Facilities have pharmacy services policies that generally comport with current professional standards with respect to packaging, labeling, and dispensation of all medications. Much of the pharmacy staff is knowledgeable and experienced. However, the adequacy of pharmacy services at the Facilities is compromised by the fact that, as discussed below, many residents receive psychotropic medication with a vague diagnosis or no diagnosis at all, which is contrary to generally accepted professional standards. In fact, many of the residents on psychoactive medications do not have a corresponding diagnosis, and the pharmacy department has no way of ascertaining the indication for the medication and cannot determine the appropriateness of the prescribed doses. Pharmacists must alert the medical staff to issues involving potential interactions, indications, and potential adverse reactions of all medications, and follow-up laboratory or medical tests.

Additionally, once a pharmacy alerts a prescribing physician of a drug interaction or possible contraindication, many Facilities do not have a standard, reliable method to track whether the physician has responded to the recommendations. While a pharmacy may contact a physician by telephone for significant findings, for all other cases, the pharmacy notes the finding and forwards the information to the physician with no standard system for ensuring that the pharmacy receives a response. The result is that Facility residents may receive inappropriate or ineffective medication needlessly.

f. Dental Services

Resident medical charts lack a comprehensive dental assessment by which to determine whether appropriate dental services are provided to residents. This is contrary to generally accepted professional standards of care. Many Facility residents do not receive regular dental x-rays. Also, many Facilities use sedating medications for dental procedures arbitrarily, without any de-sensitization programs to reduce this restraint use. This is especially problematic because some of the Facilities do not keep adequate records regarding the use of restraints or manual holds during dental procedures. Some of the Facilities' dental clinics need updated equipment. For example, the use of a single-motor suction pump is problematic because it increases risk for aspiration. This risk has heightened implications for this population because many Facility residents are already more likely to be at risk for aspiration pneumonia. We note that individuals often receive routine periodic dental

examinations, and there often is an adequate and timely response by dental practitioners when individuals complain of tooth pain. We commend the State for these practices. However, apart from response to pain, our record review unearthed instances in which necessary dental care was significantly delayed.

For instance, in May 2006, a resident of one Facility suffered shear fractures of two of his teeth. The following month, a consulting dentist recommended extraction of the teeth. The QMRP, however, reportedly failed to submit a request for approval to extract the teeth until March 2007, ten months after the fractures occurred. Separately, as of April 2007, adequate dental services reportedly had been denied to a resident since 2004 because she had not succeeded in dental desensitization. Consequently, the dentist reportedly had not examined her teeth in those three years.

g. Physical and Occupational Therapies

Facility residents are not receiving adequate physical therapy ("PT") and occupational therapy ("OT") services to meet their needs. Our review revealed that significant numbers of individuals have serious unmet needs in these areas. There are too few PT or OT therapists on staff to serve the resident population at many Facilities, 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, there is no formal system in place to inform the therapists or to trigger a PT or OT assessment or intervention. Some ambulatory Facility residents sit in wheelchairs, ostensibly to prevent falls and to facilitate transport. This is not an accepted practice and leads to regression of ambulation skills.

2. Psychiatric Services

Persons with developmental disabilities residing in state institutions have a constitutional right to "minimally adequate training." Youngberg v. Romeo, 457 U.S. at 322. In particular, "minimally adequate training required by the Constitution is such training as may be reasonable in light of [the institutionalized person's] liberty interests in safety and freedom from unreasonable restraints." Id. and at 319 ("respondent's liberty interests require the State to provide minimally adequate or reasonable training to ensure safety and freedom from undue restraint"). This right encompasses a right to receive appropriate psychiatric services to address problem behavior and

ensure that a person with developmental disabilities is not subjected to unreasonable restraints.

a. Psychiatric Assessments

Generally accepted professional standards require patients to receive an assessment, during which a psychiatrist collects and assesses relevant information to determine an appropriate psychiatric diagnosis.

Psychiatric services at the Facilities frequently fall substantially short of generally accepted professional standards of care, in part, because the Facilities simply do not have enough staff to meet the needs of resident populations. The initial assessments are extremely brief, some as short as ten to fifteen minutes. This time frame is inadequate for truly assessing the needs of the resident, compiling a detailed history, and soliciting participation from all the members of an interdisciplinary team. Often, psychiatrists do not adequately consider individuals' medical issues, physical injuries, family and psychiatric history, and comprehensive medication regime. For example in the initial assessment for one resident, T.K., in May 2008, the psychiatric medication review team praised T.K. for her weight loss. Those at the meeting appeared completely unaware that direct care staff had observed T.K. purging. In fact, direct care staff noted two weeks prior, on April 30, 2008, that she had purged "after all three meals" and that "the psychologist said that this is probably the most important behavior we should be tracking in her [Behavior Support Plan]" due to her diagnosis of diabetes and her use of psychiatric medications.

As this example illustrates, psychiatrists do not adequately consider individuals' medical issues, physical injuries, family and psychiatric history, and comprehensive medication regime. Because professional staff does not fully consider critical factors, the resulting assessments are incomplete and possibly inaccurate. Moreover, our review revealed that for most assessments, no formal note had been written or dictated, so other professionals had no way of determining the basis for the conclusions reached after the assessment.

b. Psychiatric Diagnoses

Our review demonstrated that Facility psychiatrists diagnose many residents as having psychiatric disorders based on vague diagnoses that do not comport with professional standards and do not appropriately inform treatment decisions. In particular,

many residents are identified as having Mental Disorder, Not Otherwise Specified ("NOS"),¹⁵ Intermittent Explosive Disorder and Impulse Control Disorder NOS, and other NOS diagnoses. Even where medication is prescribed, the psychiatric staff fail to identify target behaviors that the medication should address. Combined with the lack of documentation from assessments, it is impossible to determine the rationale for using the prescribed medications.

Diagnoses should inform treatment interventions, including medication choices. The absence of sound diagnoses may lead to counterproductive, even harmful, interventions, and to interventions that mask but do not correct underlying disorders. Furthermore, the import of this problem is significant considering the dangers associated with polypharmacy. We find that the quality of psychiatric diagnoses falls far below professionally accepted standards.

d. Medication Management

Regrettably, there is frequently an absence of clinical justification between the psychotropic medications prescribed to individuals and the diagnoses that they have been given. At one Facility, we identified an individual, K.X., who was receiving well over ten psychotropic medications but had not received a functional assessment to develop a proper psychiatric diagnosis justifying such medications. Staff at another Facility failed to address the fact that a resident had declined to take her psychotropic medications after stating that they made her "feel funny." Records indicate that, shortly thereafter, in May 2007, this resident hung herself with a shoestring.

e. Collaboration between Psychiatrists and Other Professionals

The lack of collaboration between psychiatrists and psychologists also severely compromises the quality of care the Facility residents receive. This custom is a substantial deviation from accepted standards of care. Too often the psychiatric medication teams make treatment decisions based on

¹⁵ The designation NOS is a "catch-all" diagnosis used when the clinician cannot or does not assign a specific psychiatric disorder but applies a generalized characterization to behavior that appears to fall within a larger diagnostic category but does not meet the criteria of any specific disorder within that category.

anecdotal reports. We also found that psychologists do not routinely attend psychiatric medication team meetings. As a corollary, psychiatric notes made no mention of psychotherapy or other non-medication related treatment options. Without a system in place to exchange information between these two disciplines, treatment altered by one specialty could destabilize treatment from the other specialty. This problem is compounded by the fact that neither discipline conducts full assessments of residents.

C. BEHAVIOR PROGRAMS AND HABILITATION

The Facilities' 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. Generally accepted professional practice requires that appropriate psychological interventions, such as behavior programs and habilitation plans, be used to address significant behavior problems and assist residents to live in more integrated settings. The Facilities fail to provide adequate psychological services to meet the needs of their residents.

In summary, the Facilities suffer from significant weaknesses in every component of psychological services. As a result, Facility residents frequently experience harm, or risk of harm, in multiple forms, as indicated the discussion above regarding pica, restraints, unjustified psychotropic medication practices, and other bad outcomes for individuals resulting from inadequate behavioral supports and services. More particularly, many Facility assessments generally fail to reliably identify individuals' needs. The assessments often are not used in developing interventions. Interventions often do not address individuals' actual needs, have adverse effects, are not monitored effectively, are not assessed in light of individuals' responses, and are not revised when warranted. Consequently, the causes of residents' harmful behaviors are often unaddressed and individuals who may be capable of more independence are not provided skills fostering independence. As a further result, Facility residents experience needlessly high rates of injurious behaviors; they are subjected to medications that have harmful side effects and that restrain, not correct, behaviors; they are subjected to other, avoidable forms of restraint; and they are denied the opportunity to live in more integrated settings.

1. Behavior Programs

Persons with developmental disabilities may engage in challenging, even harmful ("maladaptive") behaviors frequently,

especially in an institutional setting. The harm from such behaviors can be severe, even fatal. Examples include punching, slapping, scratching oneself or others, intentionally destroying property, or pica. The causes of these behaviors often reflect the primary characteristic of developmental disability - difficulty in learning, in this case, learning effective and healthy ways of meeting one's needs and wants.

The overall rates of persons engaging in serious maladaptive behaviors in the Facilities is very high. As of October 2008, the Facilities had identified over 3,277 individuals who engage in these behaviors, which equals approximately 71 percent of the population. Although some persons newly admitted to a Facility might arrive with serious maladaptive behaviors, the fact that a significant number of the Facilities' population engages in serious maladaptive behaviors demonstrates that the Facilities' behavioral supports and services suffer from major deficiencies, and that people are at risk of harm as a result.

More particularly, Facility statistics indicate that Facility residents are injured on a regular basis by another resident's aggressive behaviors. From July through September 2008, residents were victimized as a result of other residents' aggression at least 4,847 times.¹⁶ On average, that equates to more than 52 incidents of peer aggression a day. Many of the injuries were minor. However, the volume on incidents demonstrates that violent behavioral events are literally a daily occurrence at many of the Facilities. In fact, these numbers tend to underreport the problem, because they do not capture aggressive behaviors that do not result in injuries.

Separately, as noted at section III.A.1.a, above, the Facilities' documented rates of pica and attempted pica are unusually high. Further, our record review identified additional cases of pica that were not included in the Facilities' statistics, meaning actual occurrences are higher than reported. Pica often has a physiological component, but also often is behaviorally driven. Pica frequently causes intestinal damage, sometimes with fatal consequences. The Facilities' high rates of pica reflect weaknesses in their behavioral supports that expose their residents to significant harm.

¹⁶ As the investigations were initiated at different times, this total includes statistics from Denton for the period of January through April 2008 only.

Further evidence of the Facilities' difficulties in providing adequate behavioral supports to eliminate maladaptive behaviors is evident in the Facilities' efforts to restrain such behavior. As mentioned above, the Facilities over-utilize physical and mechanical restraints.

In addition, some of the Facilities are, in effect, using psychotropic medications as a form of chemical restraint. About 78 percent of Facility residents with identified maladaptive behaviors regularly receive psychotropic medications, often multiple psychotropic medications for the same diagnosed condition. This is an unusually high percentage. We did not find clinical justification for such high rates. Rather, as discussed above, the assigned psychiatric diagnoses are typically vague and frequently do not clinically correlate with the prescribed medications.

Generally accepted professional standards of practice provide that behavioral interventions should be: (1) based on adequate assessments of the causes and "function" (i.e., purpose) of the behavior; (2) be implemented as written; and (3) be monitored and evaluated adequately. Ineffective behavior programs increase the likelihood that residents engage in maladaptive behaviors, subjecting them to unnecessarily restrictive interventions and treatments. Many of the Facilities' behavior programs are ineffective and substantially depart from generally accepted professional standards. In particular, they often are not based on adequate assessments, are poorly crafted, and are not monitored, evaluated, and revised adequately.

a. Assessments

Without a thorough assessment of the function of an individual's maladaptive behavior, including clearly identified, appropriate replacement behaviors, behavioral interventions will not be successful in modifying the maladaptive behavior. As a result of the Facilities' 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.

A functional assessment identifies the particular positive or negative factors that prompt or maintain a challenging behavior for a given individual. By understanding the precursors and, separately, the purposes or "functions," 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 Facilities have recently increased their use of functional assessments. Some Facilities are also using experimental functional analyses ("EFA"), which attempt to identify through experimentation the variables leading to maladaptive behaviors. These are promising initiatives. However, many support plans lack a complete functional assessment. For instance, of the 48 support plans reviewed from one Facility, 28 lacked a complete functional assessment. Further, many of the functional assessments that were completed were based on unreliable methodologies.

Maladaptive behavior is frequently a form of communication for persons with developmental disabilities who lack the tools to communicate more conventionally. Consequently, although a complete functional assessment should address communication, a separate, reliable communication assessment should be routinely used to identify the role of communication in an individual's maladaptive behaviors and, separately, as discussed below regarding habilitation, to identify appropriate learning objectives and interventions. However, it appears from our review that communication assessments at many of the Facilities are performed only infrequently.

Relatedly, another common cause of maladaptive behavior is pain. Failure to respond timely to pain obviously leads to avoidable suffering and is recognized as contributing to increases in maladaptive behaviors. Established pain assessment tools for persons with developmental disabilities exist, but the Facilities often do not use them.

Thus, the Facilities' ability to assess and identify the factors contributing to and affecting maladaptive behaviors is excessively limited. This weakness in assessments has significant harmful consequences for Facility residents. As a threshold matter, the Facilities' clinicians lack the means to adequately understand the behaviors that they are responsible for treating, and this makes the interventions that they develop a matter of excessive guesswork. More problematically, the Facilities' weaknesses in behavioral assessments have created a treatment vacuum that has been filled by an inappropriate use of psychotropic medications.

As noted at section III.C.1. above, at 78 percent of the Facility residents who had been identified with a maladaptive behavior receive psychotropics, and many of these individuals

receive multiple psychotropic medications. Further, as discussed above, our review of the Facility residents' psychiatric diagnoses found that many are vague and unsubstantiated. In summary, the absence of adequate behavioral assessments to identify the actual cause of maladaptive behaviors has helped make this misuse of psychotropic medications possible.

b. Behavioral Interventions

According to generally accepted professional standards of care, effective behavioral interventions should target the function of the maladaptive behavior to the maximum extent possible and be built on replacing the maladaptive behavior with a healthy alternative behavior that serves the same function. To a lesser extent, behavioral interventions may include modifying the environmental causes of the maladaptive behavior. Although effective behavioral interventions typically include a means of redirecting an individual from a maladaptive behavior, this is distinct from seeking only to control or suppress the maladaptive behavior.

Behavioral interventions at the Facilities largely do not comport with generally accepted professional standards. In effect, the principal behavioral intervention used at many of the Facilities is psychotropic medication. As discussed above, behavioral assessments do not meet generally accepted professional standards of care. Nevertheless, in several instances where assessments pointed to an environmental factor (as distinct from mental illness) as the function of a behavior, the Facilities did not use this information to identify appropriate replacement behaviors or to attempt to modify the environmental factor. Further, the identified replacement behaviors were often too broadly stated to be useful. For instance, the records of one Facility indicate that the identified replacement behavior for K.P., an individual who has been identified as engaging in "inappropriate sexual behavior," was to engage in "appropriate sexual behavior." K.P.'s support plan did not define appropriate sexual behavior or explain how K.P. was to learn this replacement behavior. Separately, our review did not reveal evidence that the Facilities address maladaptive behaviors through communication training, notwithstanding that a common function of maladaptive behaviors is communication.

c. Behavioral Treatment Implementation

Consistent and correct implementation of appropriate behavioral interventions is essential. As a result of the

Facilities' high direct-support-staff attrition rate, the Facilities are severely limited in their ability to deploy staff with sufficient training and experience to consistently and correctly implement the behavioral interventions for which they are responsible. To the extent that some of the Facilities replace psychotropic medications with appropriate behavioral interventions as a principal response to the behavioral needs of their residents, the Facilities will face enormous challenges implementing those interventions if they do not stabilize their work force.

d. 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. Some of the Facilities lack the means to track critical aspects of psychological services, such as the use of restraints, the use of emergency procedures, the development and update of functional assessments, and staff implementation of programs. Some of the Facilities have no systemic tracking and analysis of the type of restrictive components contained in residents' behavior support plans ("BSP"s).

As noted above, the default behavioral intervention at many Facilities appears to be psychotropic medications. Yet, we found only very few instances where the core symptoms of the diagnosed psychiatric condition were even tracked in the resident's chart. Further, the Facilities typically lack a clinically justified methodology to track whether the medication had the targeted effect, or whether its use should be modified or paired with other interventions. As for traditional behavioral interventions, although the Facilities gather some data to assess the interventions' efficacy, the Facilities lack a standard, clinically justified method to gather data and confirm their accuracy. Potentially relevant interventions and events are not tracked consistently in assessing the causes and effects on individuals' behavior. Also, the presence or absence of replacement behaviors, which mitigate or prevent the maladaptive behavior's occurrence, are rarely tracked, and the Facilities lack a means to ensure that data are accurately and consistently reported.

Additionally, the BSPs fail to provide precise strategies for measuring the effectiveness of the plan. The outcomes

currently used by many of the Facilities to measure effectiveness are not indicators of a positive quality of life. Instead, there is a reliance on the frequency of problem behaviors. Furthermore, although the BSPs 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. This approach is contrary to generally accepted professional standards.

e. Quality Assurance and Oversight

Further, the safeguard of professional review and monitoring of behavior support services at some of the Facilities is woefully inadequate. Contrary to generally accepted professional standards of care, there is often 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. Documentation did not contain evidence of adequate reviews 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.

Separately, although the personal support plan process includes an assessment of the individual's rights, our review indicated that the Facilities' Human Rights Committees, which are responsible for reviewing restrictive interventions before implementation, approved the use of such interventions, even after noting the absence of information relevant to that approval decision. These committees' responsibility includes withholding approval for requested restrictive procedures until having an adequate understanding of the reasons for, and lack of alternatives to, such procedures, but our review indicated that this was not happening. Further complicating the lack of oversight of restrictive interventions is that many Facility residents who are subjected to restrictive or invasive procedures lack guardians to approve such procedures beforehand.

f. Psychological Staffing

Lack of sufficient psychological and behavior support services throughout the Facilities is a significant cause of problems in this area. There is a significant lack of expertise in applied behavior analysis among various members of some of the Facilities' psychology departments. The staff's inexperience is exemplified by many references in records to problem behavior

occurring for "no reason." Separately, it appears that some psychology staffing ratios are severely lacking; in some Facilities 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. Habilitation Programs

As an initial matter, many of the Facilities do not conduct cognitive assessments of their residents. Although assessments are done before admission, to validate individuals' qualification for admission, they do not address relevant factors in determining the individual's ability to learn, they are not updated in response to changes in an individual's status, and they are not used to develop basic skill-acquisition programs. This is of significant concern because the principal reason that an individual is placed at one of the Facilities, and indeed eligible for such placement, is specifically because he or she has a significant disability associated with learning. Some of the Facilities do use an assessment tool in devising habilitation goals for individuals. However, our consultant found that the reliability of this tool has not been clinically established. Relatedly, the Facilities perform vocational assessments on their residents, but these assessments are focused on individuals' deficits, rather than individuals' strengths and how those strengths can be used in a community setting.

Further, the Facilities lack a coherent methodology for determining skill-acquisition goals for their residents. Although it should be self-evident that these goals should be closely related to lowering barriers to independence and increasing individuals' safety, many of the designated self-help goals relate only tangentially to these objectives and do not reflect adequate analysis to address these individuals' most important learning priorities. For example, a current Facility training objective is for an individual to recognize a nickle and place it in his pocket. This goal does nothing to teach an individual about the purpose and utility of the nickle. (By comparison, teaching the individual how to put coins into a vending machine and obtain an item of his choice provides him with a useful skill that furthers his independence.)

Similarly, some residents are tasked with repeatedly setting and clearing a dining table. Repetitious assignments such as this, separated from any practical purpose, engender frustration, boredom, and behavioral outbursts. Groups of residents "play" games, such as "bingo," without consideration for the varying abilities of group participants. In general, we found an

insufficient focus on basic skills of independence, such as dressing oneself and learning to cross a street safely.

In addition, an important part of habilitation is learning and using skills in the environment in which those skills are useful. This is one of the most powerful motivators for skill acquisition, and this environment often will be a community setting. In fact, generally accepted professional standards of care increasingly emphasize the use of community settings for skills acquisition. Many of the Facilities currently lack the capacity to provide significant habilitation activities in the community.

Further, the quality of the selected skill-acquisition training programs at the Facilities is often strikingly poor. Generally accepted professional standards recognize that if an individual can perform a skill with the assistance of a few verbal directions, a formal skill-acquisition training program is not necessary. However, if an individual's disability is such that she requires a formal training program to acquire a particular skill, the program should be broken down into several discrete and concrete tasks that together form the basis of the skill. The skill-acquisition programs that we reviewed fell well-short of this mark. For instance, at one Facility, a skill-acquisition program for shaving consisted of one step: "shave any missed areas."

As for the implementation of the skill-acquisition programs that currently exist, our consultants found little guidance to staff as to how such programs should be taught. It appears that direct support staff are left to create their own teaching strategies, with poor success. The only written guidance to staff in implementing some objectives are vague statements about encouragement. The plans say nothing about which teaching strategies to use or avoid with the individual residents. For example, at one Facility, C.Q. has an objective to remain on task for set periods of time. The only written guidance to staff in implementing this objective is to "encourage" C.Q. Without instructing staff what to teach and how to teach it, the Facilities leave the implementation of these programs to chance. Further, this random approach leads to different staff implementing the same goal with the same individual in different ways, which encumbers learning and makes it difficult to measure and track progress.

Moreover, the amount of training that the Facilities provide falls far short of generally accepted standards of care and federal regulations, the latter of which expressly state that

"each client must receive a continuous active treatment program consisting of needed interventions and services in sufficient number and frequency to support the achievement of the objectives identified in the individual program plan." 43 C.F.R. 483.440(d)(1). The number of self-help skills designated to be taught to individuals is low.

Further, some of the Facilities provide programming on a greatly restricted basis. Many residents are scheduled to receive habilitation programming for very few hours a day, a few days a week, with extremely limited training objectives, such as pushing a button to turn a radio on and off. Staff reported that they generally implement training objectives for one trial a day. Training must include repetition to be effective. Training of such infrequency for persons with learning disabilities, such as the Facilities' residents, is pointless and likely minimally productive.

In addition, training records suggest that rates of training are even more infrequent than the schedules would suggest. Our review found significant gaps, indicating that training was either not recorded or not provided for weeks and months at a time, including goals related to life-safety issues, such as swallowing food before taking another bite. For instance, records at one Facility indicate that C.U. apparently received training on one objective only once in the month of April 2008. N.C.'s quarterly review indicated that she had received no training for the first three months of 2008 regarding several goals that her team had established the preceding December.

Additionally, tracking of individuals' progress, or lack thereof, toward identified goals is poorly done and somewhat arbitrary. Many direct care staff do not have a clear, consistent understanding of the criteria for measuring individuals' progress. Training plans often lacked a coherent, understandable explanation as to how success was to be measured. It is largely useless to attempt to track progress is without a clear, objective, and understood standard by which to measure such progress.

Finally, related to habilitation and active treatment is the provision of vocational services. Providing individuals with meaningful activities and opportunities for personally satisfying work strengthens their skills of independent living and powerfully motivates appropriate behaviors. Largely due to resource limitations, the Facilities provide only a small fraction of their residents with vocational opportunities, both on campus and in the community. Only a very small percentage of

residents have jobs in the community. Many Facility residents have been assessed as being capable of working, interested in working, and likely to benefit from working. Yet, most of these individuals were unable to work, or to work beyond a few hours each day, according to their records, because of space and other resource limitations.

3. Communication

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, and hinders individuals' ability to be integrated into community settings. Although some recent initiatives are dedicated to addressing this deficiency, the Facilities typically fail to provide residents with adequate and appropriate communication services.

As noted above, communication assessments frequently are not performed when warranted. In fact, records at one Facility indicate that only 23 communication assessments have been performed, even though the Facility's population is several hundred residents. Further, there has been no substantive collaboration between the speech and psychology staff regarding needed communication supports. Given that behavior often serves a communication function, this lack of coordination reflects a significant deficit in the provision of adequate behavioral interventions. Communication aids for individuals lacking communication skills are frequently not provided to individuals who need them, staff do not know how to use them, and the devices are often inoperable. Further, although communication assessments included helpful "Staff Communication Instructions," these instructions were not included in the individual's personal support plan, and we found no other plan through which they were to be implemented.

D. INTEGRATED SUPPORTS AND SERVICES AND PLANNING

Many of the Facilities' difficulties in providing adequate supports and services to residents stem from the Facilities' failure to ensure that the relevant disciplines both receive and consider the appropriate information. We encountered numerous examples where relevant information that should have been

considered in developing interventions was not. For instance, although some individuals' functional assessments indicated their behavior was not related to any mental illness, the Facilities did not consider this information in determining whether the individuals had a mental illness.

The Facilities have begun moving toward a "person-centered planning" process and have made progress with this initiative. Annual planning meetings are facilitated by persons who are well acquainted with the individual resident, the Facilities make efforts to include the resident in the meetings, and team members are respectful of the resident and his or her expressed preferences. Some Facilities have taken the positive step of initiating a peer review process of the overall individual planning process.

Although these are encouraging steps, the Facilities typically engage in a planning process devoid of effective communication across disciplines that enables them to respond adequately and effectively to the individual's needs. A clear example of this problem is the Facilities' failure to integrate communication services with behavioral supports, notwithstanding that communication is often the central function of challenging behaviors. This breakdown contributes to the Facilities' high use of restraints and other restrictive interventions. It also leads to suspect diagnoses. We found numerous examples of breakdowns in basic coordination of care. For instance, at one Facility, T.K. has several medical problems, such as diabetes, high blood pressure, high cholesterol, and obesity. Yet, her most recent annual personal support plan was developed without her physician's input or even a physical assessment. She also has been identified as having significant behavioral problems. Although psychology staff participated in her annual planning meeting, her annual support plan was developed without a psychological assessment or behavior support plan. Further, T.K. receives psychotropic medications and was admitted to the Facility from a psychiatric hospital. Notwithstanding her apparently significant psychiatric issues, her psychiatrist provided no input into the creation of her annual support plan. In fact, the team did not have a psychiatric assessment as of the annual planning meeting. We found numerous additional examples of such basic breakdowns in coordination of care. This is a fundamental problem that must be corrected before real progress can occur in ensuring that individuals receive the supports and services they require.

E. SERVING RESIDENTS IN THE MOST INTEGRATED SETTING

In addition to providing residents with adequate safety, training and behavioral services, freedom from undue restraints, psychiatric care, health care, and other related supports and services, federal law requires that the State actively pursue the timely discharge of institutionalized persons to the most integrated, appropriate setting that is consistent with those persons' needs. We found that Texas fails to serve Facility residents in the most integrated setting appropriate to their individualized needs, in violation of Title II of the ADA and the regulations promulgated thereunder.

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.

The regulations promulgated pursuant to the ADA provide: "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d) (the integration regulation). The preamble to the regulations defines "the most integrated setting" to mean a setting "that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." 28 C.F.R. pt. 35, App. A at 450.

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 Facilities' residents, the State of Texas has not taken adequate steps to promote and provide adequate community placements. Despite a total census of over 4,500 residents, only 164 individuals moved from the Facilities to the community in the period from September 2007 to September 2008.¹⁷ This is less than four percent of the total population. This small number of placements is troublesome because (1) many Facility residents are very capable individuals who are not difficult to place and (2) while some Facility residents have unique care considerations and face more barriers to placement than others, our experts unilaterally agree that many Facility residents with more profound health and physical care needs could indeed live in community settings if provided the appropriate protections, supports, and services.

We found several barriers to the State's ability to ensure the Facility residents' right to receive services in the most integrated setting appropriate to their individual needs to include: (1) lack of an adequate admissions process; (2) lack of community placement knowledge among treatment teams and the Facilities' failure to communicate community options and available resources to residents, guardians, and family members; (3) deficiencies in the Facilities' annual planning process concerning discharge/transition planning; and (4) ineffective quality assurance mechanisms in the community.

1. Lack of an Adequate Admissions Process

The Facilities and the State appear to lack a formal diversion process to ensure that persons with mental retardation are considered for community-based services prior to being admitted to an ICF/MR. Before an individual can

¹⁷ As the investigations were initiated at different times, this total includes statistics from Denton for January through April 2008 only.

receive services at a Facility, a court order for civil commitment is required. However, the State does not ensure that individuals are considered for, or even informed about, viable community placements as an alternative to a large institutional setting before they engage in the court commitment process that results in admission to a Facility. For example, T.K., noted above, was admitted to a Facility in April 2008, from a Kansas state mental hospital. T.K.'s personal support plan, developed a month after her arrival to the Facility, contained a detailed description of the supports and services a community provider would need to offer T.K. for her to have an appropriate community placement. T.K.'s records also reveal she had previously lived on her own, in a group home, and with family. Although the Facility has identified the supports and services T.K. requires and she has lived in more integrated settings previously, nothing in T.K.'s records indicates that she was ever considered for community-based services prior to her commitment to the Facility. An adequate admissions process requires an assessment regarding the appropriateness of the placement.

It is important to note that, once a civil commitment to one of the Facilities occurs, it appears that the decision is never reviewed by either the court, the Facility, or any other State entity. In fact, there are individuals who have resided at the Facilities since the 1960s without the Facilities ever requesting a formal judicial review of their commitment to the Facility. Failure to consider the appropriateness of the placement prior to or after their admission to a Facility has likely resulted in the unnecessary or prolonged institutionalization of individuals who could live successfully in the community.

2. Inadequate Knowledge and Education about Community Placement Options

Many of the Facilities' interdisciplinary teams lack sufficient knowledge of the community placement options available to individuals. As a result, Facility residents, along with their families and guardians are denied opportunities to learn of supports and services that would enable individuals to live in the most integrated settings appropriate to their individual needs. At some of the

Facilities, teams operated as if they must either recommend or not recommend community placement. By taking this all-or-nothing approach, these teams fail to consider many options that are available to an individual. Teams also are not adequately educating individuals' family or guardians on available community options, facilitating visits different community settings (i.e., group home, independent apartment living, or family placement), or consulting with providers regarding the services available within the community.

We found that many Facility residents or their families or guardians reject the idea of community placement due to misinformation and lack of information about the community placement options and available supports and services available outside of an institutional setting. The Facilities fail to adequately address the reluctance to community placement by providing clear information on the community placement process and explanations of how real or perceived barriers to community placement will be addressed in order for the individual to reside in the community. For example, records from one Facility indicate that, in his June 2007 PSP meeting, C.U. indicated that he has become more interested in moving to the community. His guardians, however, felt that the Facility is a safe environment, that C.U. has made much improvement at the Facility, and that C.U. sees the Facility as his home. The team noted that C.U.'s guardians were not interested in exploring alternate placement options at the time. Despite the fact that the team stated that, in all key areas, C.U.'s needs could be met in a more integrated community setting, they recommended that he continue to reside in his current placement, and did not recommend any actions to assist C.U. or his guardians to learn more about the available community options. The Facilities and the State must ensure that Facility residents and persons responsible for making care decisions for these individuals are fully informed about community-based services, supports and living options, and are fully involved in team meetings discussing these issues.

To its credit, the State has implemented a number of new processes to ensure individuals and their representatives are informed about their options and given choices with regard to the provision of supports and services in community settings. These initiatives, however, are at the very early stages of

implementation and require further development and assessment of their effectiveness. Beginning in March 2008, the local Mental Retardation Authorities ("MRAs") have designated staff, Community Living Option Specialists, meet with individuals residing at the Facilities and their families or guardians to discuss community options, and complete an options checklist prior to each individual's annual personal support plan meeting. The MRA staff is now attending annual personal support plan meetings and presenting the findings from a community options checklist to teams, resulting in more options for treatment teams to consider when deciding whether to make a direct referral for community placement or to take interim steps to explore and develop a plan around the available community options.

3. Ineffective Discharge and Transition Planning

The Facilities and the State must provide adequate discharge and transition planning for community placements. Determining the necessary supports and services an individual needs to live successfully in the community must be done as part of the annual planning process, not once a recommendation for community placement has been made. The discharge and transition plans must also identify the supports and services that need to be in place soon after an individual moves to the community. The Facilities have not yet implemented an effective discharge and transition planning process. We reviewed personal support plan documentation where essential supports were identified for an individual were unclear or inadequate, thereby creating unnecessary difficulty for the treatment teams and community providers in determining the existence of supports in the community. For example, a Facility resident, S.C., indicated in his November 2007 PSP that he would like to move to the community, but only if a community setting would meet all his needs. His team developed an action plan in conjunction with the MRA to provide S.C. and his team a list of providers who could meet his care and service needs. However, a number of essential supports were not adequately explained or addressed in S.C.'s PSP. Specifically, S.C.'s PSP contained only vague statements concerning essential medical and nursing needs, lacked important transport safety information, or ways to address S.C.'s risk of falls when living in the community. From the PSP, it was impossible to discern how, when, or if

the essential supports S.C. required would be made available to him in the community.

4. Ineffective Quality Assurance Mechanisms

From our review, it appears that the State relies heavily on the MRAs to conduct annual self-assessments of the community providers with whom they contract. Although the State conducts periodic external reviews, the Facilities and the State should examine more closely the evaluation tools and processes used by MRAs to assess the adequacy of community placements. We found instances where Facility social workers were in regular contact with service providers and case managers, but failed to document that all essential supports or services were in place before the individual was discharged to the community. When Facility social workers do identify areas in which essential supports are not provided, it is unclear whether follow-up occurs to ensure the provision of the essential support.

For example, D.I.'s discharge plan outlined the supports and services needed to achieve his desired outcomes, including that the provider would assist D.I. in locating a work program that will increase his vocational participation and provide a wage. The Facility social worker's notes from D.I.'s 30-day planning meeting indicated that D.I. was enrolled in a day habilitation program three days a week and volunteered with the Meals on Wheels once a week. While the Meals on Wheel volunteer opportunity potentially provides a component of vocational training for D.I., none of these day time activities meet the criteria of allowing D.I. to earn a wage. The social worker's notes also did not indicate if anything additional would be done to ensure that D.I. was provided with adequate vocational opportunities and an effective placement.

When community placements are unsuccessful, residents and their families or guardians, and even Facility and State staff, may erroneously assume that quality services are not provided in the community, thus deterring teams from recommending community placement for the individual or other residents in the future. The State must ensure that minimal quality assurance mechanisms are in place and that providers of residential and day or vocational supports are not left to

police and determine the quality or effectiveness of their programs or services themselves. Community living supports and services require the appropriate, unbiased oversight of the State if placements for individuals who are able and desire to reside in the community are to have the best chance of success.

IV. REMEDIAL MEASURES

To remedy the identified deficiencies and protect the constitutional and statutory rights of the Facilities' residents, the State should implement promptly, at a minimum, the remedial measures set forth below. Because the deficiencies identified above are similar to those that the Department found in its December 11, 2006 findings letter regarding Lubbock State School and the State wishes to take a systemic approach to resolving the identified deficiencies, these remedial measures closely mirror those set forth in that letter.

A. Protection from Harm

Incidents involving injury and unusual incidents should be reliably and accurately reported and investigated, with appropriate follow-up. More particularly, the Facilities 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.
5. Ensure that dissemination of information regarding open investigations is limited to staff essential to the investigatory process.

B. Health Care

1. General Medical Services

The State should ensure that residents of the Facilities receive routine, preventative, and emergency medical and dental care consistent with current, generally accepted professional standards. The Facilities 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 Facilities 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 the

Facilities' 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 and dental x-rays, as appropriate, are conducted and recorded in the medical record.

**2. Occupational and Physical Therapy Services/
Physical and Nutritional Management**

The State should ensure that residents of the Facilities receive adequate and appropriate assessment and treatment by occupational and physical therapy services consistent with current, generally accepted professional standards of practice. The Facilities 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 Facilities 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 the Facilities 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 Facility staff who assist individuals with dysphagia or choking risks.

3. Psychiatric Services

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 Facilities 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 the Facilities, 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 Facilities 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 desensitization 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.

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, the Facilities 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, the Facilities 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 and straight jackets 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

The Facilities should provide 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, the Facilities should:

- a. Formalize habilitation planning protocols, policies and procedures consistent with generally accepted professional standards of care for use throughout the Facilities.
- 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. Serving Persons in the Most Integrated Setting Appropriate to Their Individualized Needs

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 the Facilities. Assessments (for new admissions) should be done at admission. Periodically update the assessments for individuals who remain at the Facilities 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 the Facilities.

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 ten calendar days from the date of this letter.

Provided our cooperative relationship continues, we also would be willing to send our expert consultants' evaluations 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, 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 49 days after appropriate officials have been notified of them. 42 U.S.C. § 1997b(a)(1). We would prefer, however, to resolve this matter by working cooperatively with you, 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/ Grace Chung Becker

Grace Chung Becker
Acting Assistant Attorney General

cc: The Honorable Greg Abbott
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