



**U.S. Department of Justice**

Civil Rights Division

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

November 9, 2009

The Honorable Pat Quinn  
Governor  
Office of the Governor  
207 State House  
Springfield, Illinois 62706

Re: Investigation of the Clyde L. Choate Developmental Center,  
Anna, Illinois

Dear Governor Quinn:

I am writing to report the findings of the Civil Rights Division's investigation of conditions and practices at the Clyde L. Choate Developmental Center ("Choate"), in Anna, Illinois. On February 27, 2007, we notified then Governor Blagojevich of our intent to conduct an investigation of Choate pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. CRIPA gives the Department of Justice authority to seek remedies for any pattern or practice of conduct that violates the constitutional or federal statutory rights of persons with developmental disabilities who are served in public institutions.

On July 23-26 and September 17-20, 2007, we conducted an on-site review of care and treatment at Choate with expert consultants in various disciplines. During our visits, we interviewed Choate administrators, professionals, staff, and consultants, and visited residents in their residences, at activity areas, and during meals. Before, during, and after our site visits, we reviewed a wide variety of relevant State and facility documents, including policies and procedures, incident reports and investigations, and medical and other records relating to the care and treatment of Choate residents. In keeping with our pledge of transparency and to provide technical assistance, where appropriate, we conveyed our preliminary findings to State counsel and to certain State and facility administrators and staff during exit briefings at the close of our on-site visits.

We would like to express our appreciation to Choate administrators, professionals, and staff and to the State officials who participated in our visit for their assistance, cooperation, professionalism, and courtesy throughout our

investigation. We hope to continue to work with the State and Choate officials in the same cooperative manner going forward.

In accordance with statutory requirements, we now write to advise you formally of the findings of our investigation, 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). In doing so, we note that many of the findings we make in this letter are due to or exacerbated by Choate's failure to focus its treatment and care on moving individuals into the most integrated settings appropriate to their needs in violation of Olmstead v. L.C., 527 U.S. 581 (1999), including failures in: (A) behavioral, intellectual, communication, and psychiatric assessments; (B) behavioral interventions; (C) treatment planning; and (D) habilitation, communication, and special education programs and services. These deficiencies place individuals at greater risk of injuries related to their or others' maladaptive behaviors and make restrictions on their liberty due to use of seclusion or restraint more likely, undermining the treatment provided at Choate and potentially leading to prolonged institutionalization.

Based upon our investigation, we have concluded that certain conditions and practices at Choate violate the constitutional and federal statutory rights of its residents. In particular, we find that Choate fails to provide its residents with adequate: (A) transition planning and placement in the most integrated setting; (B) protection from harm; (C) health care, including psychiatric care and physical and nutritional management; (D) behavioral, habilitation, and communication services; (E) special education services; and (F) integrated treatment planning. See Olmstead v. L.C., 527 U.S. 581 (1999); 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. §§ 12101, 12132 et seq.; 28 C.F.R. § 35.130(d); Individuals with Disabilities Education Act ("IDEA"), 20 U.S.C. § 1401 et seq.; and Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794.

Despite these deficiencies, we wish to note several positive aspects of the care that Choate provides to its residents. Choate's grounds and buildings are well kept, and the living units are clean and presentable. Beyond these aesthetics, we also found that many of the staff members we interacted with showed genuine care and respect for Choate's residents, and we were impressed with clinical abilities of many of Choate's medical professionals, including the Director of Nursing and the Medical Director. Likewise, the forensic unit at Choate is impressive in many respects, particularly in its focus on habilitating its forensic residents so that they can move as expeditiously as possible to less restrictive settings appropriate to their needs.

Nevertheless, two significant concerns underlie many of the findings we set forth in this letter. First, we found a critical lack of oversight and supervision pervading most aspects of the care and treatment provided at Choate. This derived, in part, from vacancies in certain key positions. More fundamentally, however, we found that Choate is not collecting, analyzing, and synthesizing information adequately so that its administrative and clinical leadership can accurately determine whether Choate's residents are safe, whether their needs are being met, and whether the treatment and habilitation provided at Choate are effective. The failure to collect and analyze information adequately has also undermined Choate's ability to integrate information across disciplines and provide coordinated and collaborative care. These failures have led to substantial constitutional violations.

Second, we noted a profound inattentiveness to Olmstead's requirement of placing residents at Choate in the most integrated setting consistent with their needs. Generally accepted professional standards and federal law require that the treatment of individuals with developmental disabilities be focused on the development of skills and abilities that aid those individuals in overcoming their personal barriers to living as independently as possible. Thus, a focus on helping individuals move to live successfully in more integrated settings should underlie all aspects of the care and treatment provided at Choate. Unfortunately, unlike Choate's forensic unit where movement to more integrated settings appears to be emphasized, we found that this emphasis did not characterize the provision of treatment at Choate generally. As previously noted, many of the findings we make in this letter are aggravated by Choate's failure to focus its treatment and care on moving individuals into the most integrated settings appropriate to their needs.

## I. BACKGROUND

Located in Anna, Illinois, approximately 105 miles outside of St. Louis, Missouri, Choate is a licensed 200-bed intermediate care facility for individuals with developmental disabilities. Choate is one of nine residential developmental centers operated by the Illinois Department of Human Services ("DHS"). Choate also operates the State's only forensic unit for individuals with developmental disabilities, which has a total bed capacity of 30 residents. At the time of our visits in July and September 2007, Choate housed approximately 175 residents. In addition, DHS operates a psychiatric hospital on the Choate campus, but that hospital was not included in our review.

## II. FINDINGS

### A. Choate's Transition and Discharge Planning Is Inadequate

Choate fails to provide transition and discharge planning consistent with federal law. This failure to provide adequate transition and discharge planning was made evident when we requested a "list of all residents with community placement goals" during our visit, and we were provided a list that only included the names of six individuals out of the 175 individuals residing at Choate. Moreover, the monthly review meetings we attended and the monthly review summaries we reviewed included virtually no discussion of discharge planning, and when they did discuss it, they cited inappropriate barriers to discharge, such as weight management and management of diabetes, neither of which prevent community placement. The failure to provide adequate discharge planning deprives the individuals confined at Choate of their rights under Olmstead. The State's failure to comply with Olmstead also contributes significantly to the constitutional violations we identify in the remainder of this letter.

Federal law requires that Choate actively pursue the timely discharge of residents to the most integrated, appropriate setting that is consistent with the residents' needs. Olmstead, 527 U.S. at 607. Thus, at the time of admission and throughout a resident's stay, Choate should: (1) identify, through professional assessments, the factors that likely will foster viable discharge for the resident; and (2) use these factors to drive treatment planning, habilitation, and intervention. Without clear and purposeful identification of such factors, residents will be denied habilitation and other services and supports that will help them acquire, develop, and/or enhance the skills necessary to function in a community setting.

The Choate discharge planning process substantially deviates from generally accepted professional standards and federal law. The inadequacies in Choate's discharge planning process are intertwined with the other deficiencies in the care and treatment provided at Choate: the failures in other disciplines undermine Choate's ability to place individuals in the most integrated setting, while the failure to move individuals to the most integrated setting consistent with their needs is a fundamental cause of the constitutional violations in the care and treatment provided at Choate. As discussed in further detail in Section II.D.1.a, infra, Choate's behavioral, intellectual, and communication assessments are inadequate, undermining Choate's ability to determine the strengths and needs of individuals so they can be placed in the community. Choate does not appear to be performing these assessments on a timely basis, nor does it appear to be focused on determining the barriers to returning the individual to a community setting.

Relatedly, Choate's psychiatric assessments, diagnoses, and monitoring of psychotropic medications are inadequate, suggesting that the use of these medications may be counter-therapeutic in some instances, as discussed in further detail in Section II.C.2. In particular, the failure to attempt to determine minimally effective dosages suggests that individuals may be receiving inappropriately high dosages of medications that are being used to restrain, rather than treat, maladaptive behaviors, and that inhibit the ability to treat the maladaptive behavior through appropriate behavioral interventions. The unjustified use of psychotropic medications can significantly impair the other treatment and habilitation provided at Choate, and hinder an individual's ability to move to a more integrated setting.

Because Choate fails to provide adequate behavioral, intellectual, communication, and psychiatric assessments, the behavioral interventions based on those assessments are inadequate as discussed in further detail in Section II.D.1.b, and the interventions do not assist individuals in developing the skills they need to be able to live in a more integrated setting. Indeed, as discussed in further detail in Section II.D.1.b, we found many instances where individuals were receiving inappropriate or insufficient behavioral interventions, including multiple examples where individuals had been identified as having significant maladaptive behaviors but were not receiving any structured behavioral interventions. The failure to implement timely and appropriate behavioral interventions often leads to regression in the functional abilities necessary to live in a more integrated setting and, as discussed in further detail in Section II.B.3, may lead to further restrictions on an individual's liberty, including seclusion and restraint. Further, the failure to implement appropriate behavioral interventions places these individuals at risk of injuries related to their or others' maladaptive behaviors, which may hinder their treatment at Choate and lead to prolonged institutionalization.

Moreover, we found that the habilitation programs at Choate do not meet constitutional standards as discussed in further detail in Section II.D.2. Choate's provision of continuous active treatment is infrequent and is not designed to meet the habilitation needs of the individuals residing at Choate adequately. Relatedly, in our review of the Personal Service Plans ("PSP") at Choate, as discussed in further detail in Sections II.D.2 and II.F.1, *infra*, we found that they lacked any section devoted to discharge planning. Treatment of individuals at Choate should be focused on the barriers to community placement and the provision of skills to overcome those barriers. Therefore, while Choate does identify some barriers to community placement in the PSPs, the PSPs do not list specific plans to address those barriers. Relatedly, the monthly review meetings of the treatment teams do not routinely address discharge planning and barriers to placement. The failure to focus treatment planning, habilitation, and interventions on enabling the individual

to return to the community is a substantial departure from generally accepted professional standards and the requirements of Olmstead.

We also found that Choate's provision of communication services, including speech and language programming and services for individuals with hearing impairments, did not meet generally accepted professional standards, as discussed in further detail in Section II.D.3. The development of communication skills greatly facilitates movement toward more integrated settings for individuals with developmental disabilities, as it is these skills that enable them to communicate their needs and concerns and to avoid engaging in maladaptive behavior that may lead to prolonged institutionalization. Effective communication skills enable the individual to become less dependent on others for their basic needs, including medical care, and to access essential services at the time of their choosing, which are required for living in less restrictive settings.

Finally, Choate's failure to provide adequate special education services hinders individuals' ability to live in more integrated settings, as discussed in further detail in Section II.E. Education is both an aspect of living in the most integrated setting and an essential means of obtaining the skills necessary to live in such a setting. Individuals residing at Choate have a right to special education services under federal law, and the failure to provide those services impairs their ability to participate and integrate into more integrated settings.

## **B. Choate Does Not Adequately Protect Individuals From Harm**

The Supreme Court has recognized that persons with developmental disabilities who reside in state-operated institutions have a "constitutionally protected liberty interest in safety." Youngberg, 457 U.S. at 318. Therefore, as the Court explained, the state "has the unquestioned duty to provide reasonable safety for all residents" within the institution. Id. at 324. In our judgment, Choate fails to provide a living environment that complies with this constitutional mandate.

Choate does not adequately protect its residents from harm and risk of harm and does not provide its residents with a reasonably safe living environment. Specifically, individuals residing at Choate are subject to repeated injuries of similar nature, unchecked self-injurious behavior, abuse, and neglect. The harm Choate residents experience as a result of these deficiencies is multi-faceted and includes physical injury; psychological harm; excessive and inappropriate use of restraints; and inadequate, ineffective, and counterproductive treatment. This harm undermines the other care and treatment provided at Choate, prolongs the time period spent by individuals in the institution, and delays the movement of individuals to more integrated settings in violation of Olmstead. The facility's

ability to address this harm is hampered by inadequate incident, risk, and quality management and deficient investigative practices.

1. Incident and Risk Management Is Inadequate

Choate's incident and risk management systems are inadequate to protect its residents from harm. To ensure that residents' constitutional right to safety is protected, generally accepted professional standards require that residential developmental disability facilities maintain an incident and risk management system that seeks to prevent incidents and requires appropriate corrective action when incidents do occur. Effective incident and risk management depends on: (1) accurate data collection and reporting; (2) thorough investigations; (3) identification of actual or potential risks of harm, including the tracking and trending of data; and (4) implementation and monitoring of effective corrective and/or preventive actions. The incident and risk management system at Choate falls significantly short of these standards and, as a result, residents are exposed to actual and potential harm.

a. Incident Reporting Is Deficient

Our review of Choate's incident reporting process found significant deficiencies resulting in substantial underreporting of incidents, events, and risks that affect the health and safety of residents at Choate. These deficiencies are caused by a procedural and policy failure to require that all incidents are reported to quality assurance personnel, as well as a lack of understanding of incident reporting guidelines by Choate staff.

First, according to policy, Choate only collects and analyzes incident data when an injury occurs. Choate limits incident types to accidents, peer-to-peer aggression, self-injurious behaviors, and injuries of an unknown origin. Therefore, for an incident to be included in an individual's data, and thus in the facility's aggregate data, an individual must have been harmed to such an extent that an Injury Report was warranted. The failure to include incidents that do not include an injury precludes Choate from being able to conduct analyses before an injury occurs, anticipate potential areas of harm, and take corrective action. To the extent that Choate's incident reporting policies only require incidents that result in injury to be reported, they substantially depart from generally accepted professional standards and promote constitutional violations.

Second, during our tour of Choate, we also found a lack of staff awareness about the current incident reporting policy. We were initially advised that the incident reporting policy had either just been revised or was under revision, but nevertheless all staff had been trained on the new policy and were expected to

implement it. When we requested a copy of the policy, we were informed that the policy was not yet available. During our tour of the facility, however, a unit director indicated that a policy notebook had just recently been provided, but it was kept in the unit director's office, not on the unit. According to the unit director, training on the new policy was to begin the following week. When asked about the contents of the new policy notebook, the unit director indicated that he had not yet reviewed it. The level of confusion regarding incident reporting suggests that incident reporting is not being performed uniformly, casting considerable doubt on the reliability of the data collected in these reports.

Our review of Choate's incident report data in conjunction with individuals' clinical records, external notification reports, and similar sources indicated that the incident reporting data were unreliable. A significant number of incidents and injuries are not being received and reported in the facility's aggregate data used for tracking and trending.<sup>1</sup> For example, the following incidents were found in clinical records or external notification reports, but were not included in an individual's or the facility's aggregate data:

- On April 3, 2007, an individual complained of ear pain and a plastic object was discovered in the ear canal, requiring removal by an Ear, Nose, and Throat Specialist;
- On April 6, 2007, an individual fell and sustained two lacerations to his forehead that required sutures;
- On July 11, 2007, a resident's lip was lacerated after being punched by another resident; and
- On July 17, 2007, a resident threw a chair at a peer, hitting him in the face, and first aid was necessary.

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<sup>1</sup> We also found that Choate's aggregate data on restraint usage is not an accurate reflection of actual restraint use at the facility. For example, we were provided with a report purporting to show restraint usage by person from January 1, 2006 through July 26, 2007, but we found a number restraints documented elsewhere in facility records that were not included in this report.



Over time, the failure to properly report all incidents is even more troubling, as demonstrated by the following examples:

- Between April 1, 2007, and July 23, 2007, an individual was reportedly injured on three occasions, but a thorough record review revealed injuries on at least eleven separate occasions; and
- Between April 1, 2007, and July 23, 2007, according to the report data, a resident only had one incident of “attempted pica,”<sup>2</sup> while other records, including radiology reports and three internal investigations into alleged neglect, revealed that the resident had successfully ingested a necklace on May 20, 2007, and a metal screw on May 21, 2007. In several other instances recorded in progress notes, the resident threatened pica behavior, and in one instance punched a staff member in the mouth when the staff member attempted to redirect him. None of these “threatening pica” incidents was recorded in his behavioral tracking data.

Choate’s failure to properly report these incidents jeopardizes its ability to identify potential risks of harm and institute appropriate intervention strategies. Indeed, in the latter example, if some of the “threatening pica” behaviors had been correctly reported and tracked in the resident’s behavioral data, it is possible that the ingestion of the necklace and screw could have been prevented through timely intervention. Choate’s failure to report adequately incidents and injuries departs substantially from generally accepted professional standards and violates the constitutional rights of the individuals who reside at Choate.

b. Choate Fails to Identify Risk of Harm and Implement Preventive Actions

While incident management focuses on the collection and aggregation of data that are meaningful to protect an individual from harm, risk management focuses on identifying actual or potential harm from that data and taking timely action to prevent the harm from occurring. Specifically, risk management involves: (1) identification of actual or potential risks of harm based on historical data, diagnoses, and co-morbid conditions; (2) timely and appropriate intervention strategies designed to reduce or eliminate the risks of harm; and (3) monitoring of the efficacy of the intervention strategies and modifying the strategies in response to further data. Choate fails to provide adequate risk management to its residents.

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<sup>2</sup> Pica is a medical condition in which a person ingests or attempts to ingest nonfood substances such as clay, chalk, hair, or glue.

The rate at which harm is occurring, combined with the patterns of the harm, indicate that Choate is failing to identify risks of harm and intervene in a timely manner. Although Choate's incident and injury data are significantly underreported, as described in the previous section, even the data that are reported show that incidents and injuries are frequent and severe. For example, from January 1, 2007, to March 31, 2007, a 90-day period, one individual suffered 42 injuries from self-injurious behaviors, "accidental events," or assaults by peers. The number of injuries increased each month, from 11 in January, 14 in February, to 17 in March. Another individual, a forty-three-year-old blind resident with severe mental retardation, sustained injuries on ten different occasions from April 2007 to June 2007, including a head laceration, a fractured thumb, and multiple abrasions and bruises. Incidents and injuries occurring with such regularity and severity suggest a failure to identify actual or potential risks to individuals and to respond with appropriate interventions.

Even where risks have been identified, however, Choate has inadequately addressed these risks. During our tour, we discovered one individual, A.A.,<sup>3</sup> whose September 2006 Individualized Program Plan ("IPP") noted that she had sustained several injuries during the past year during transfers, because she is not cooperative with the procedure. The Physical Therapy section of the September 2006 IPP noted that "it is harder for one person to transfer" A.A. Nevertheless, no plan was instituted to prevent further injuries, and one-person transfers continued. Throughout 2007, A.A. continued to suffer injuries during transfers, including bruises, scratches, and lacerations. Only after A.A. suffered a head laceration from a fall during a one-person transfer in July 2007 did a physician order that all future transfers be performed by two people. Having identified that A.A. was at risk of harm during transfers in September 2006, ten months before the physician's order, Choate's failure to intervene in a timely and appropriate manner deviates substantially from generally accepted professional standards and violates A.A.'s constitutional rights.

The intervention strategies that Choate has implemented are also not monitored sufficiently to ensure that they prevent recurrences of potentially harmful behavior. For example, a resident who inserted a metal needle and a plastic pick into her ears in response to ear irritation, causing bleeding in her ears, was placed on 24-hour supervision and had all personal belongings confiscated that could potentially be placed in her ears. Approximately ten days later, after the ear

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<sup>3</sup> To protect individuals' privacy, we identify them by initials other than their own. We will separately transmit to the State a schedule that cross-references the initials with individuals' names.

infection subsided, all monitoring ceased and her belongings were returned. The individual continued to complain about ear irritation for the next two months, but no measures were taken. The resident was then found bleeding from one ear, and an object was discovered deep inside the inner ear canal which had to be removed by an Ear, Nose, and Throat Specialist. The short-term intervention of 24-hour supervision and removal of certain objects was insufficient to prevent the potential for future harm, and no further intervention was devised despite the resident's ongoing ear complaints.

In short, we found that individuals suffer harm as a result of Choate's substantial departure from generally accepted professional standards in the three main components of risk management: risk identification, timely interventions, and monitoring of outcomes. These conditions violate the Constitution.

c. Investigative Practices Are Deficient

Constitutional mandates and generally accepted professional standards dictate that facilities like Choate investigate serious incidents such as alleged abuse and neglect, serious injury, and death. During the investigation, evidence should be systematically identified, collected, preserved, analyzed, and presented. Investigators should attempt to determine the underlying cause of the incident by, among other things, reviewing staff's adherence to programmatic requirements such as policies and procedures. Such investigations are necessary to comply with an institution's duty to provide reasonable safety.

The investigative process at Choate substantially departs from these standards. As an initial matter, we noted during our tour that, in many cases, Choate permits staff against whom allegations have been made to return to duty before the investigation is complete or a well-supported, preliminary determination that the employee poses no risk to individuals or the integrity of the investigation has at least been made. Even though Choate indicates that this is only done when there is no credible evidence immediately available to support the allegation, this practice is still troubling. It permits a staff member who has been accused of abuse or neglect to potentially commit further abuse or neglect if the preliminary decision to return them to their normal job was incorrect. Furthermore, it affords the staff member the opportunity to contaminate the investigation through coercion of potential witnesses, whether that coercion is real or merely perceived. Choate should not continue to permit this practice.

Moreover, Choate's actual investigations substantially depart from generally accepted professional standards in violation of the Constitution. Our review of Choate's investigations from November 2006 to July 2007 revealed that, out of 81 investigations conducted, not a single one of the allegations of abuse or neglect was

substantiated. Although there is an option for reconsideration of investigative findings, Choate has not requested reconsideration since 2005. The complete lack of substantiation of abuse and neglect allegations is suggestive of incomplete and inadequate investigations.

Our review confirmed that the investigations are indeed inadequate. We found numerous cases where questionable inferences were drawn based on the facts presented, and many in which relevant questions were left unanswered. For example, an individual who eloped from Choate in March 2007 was aided in that effort by a staff member with whom he had an ongoing relationship. After the elopement, the individual and staff member went to the staff member's home and had sexual relations. According to the resident, sometime following his elopement, but while he was still at the staff member's home, someone from Choate called the staff member to inform her that the resident had eloped. While it is possible that this was merely a routine phone call to a staff member who knew the resident, it strongly suggests that someone at Choate was aware of the relationship between the staff member and the resident. There is no indication in the investigative record that anyone sought to determine who the caller was, or why that person would place a call to the staff member's home. Since the staff member has now been charged with sexual assault of a minor, it is possible that the caller was an accessory to the alleged crime, yet no follow-up was performed. This is a serious oversight in the investigative process. It is also noteworthy that neither of the staff members responsible for checking the resident's bed every 15 minutes had an allegation of neglect substantiated by investigators, even though the State regulatory agency required Choate to retrain both of them on this process.

Another example of inadequate investigations involves a pica incident, referenced earlier, in which an individual ingested a necklace. Despite two eyewitness accounts by Choate residents stating that they observed a nurse leave the necklace on a table and then saw the individual pick it up and swallow it, Choate's investigators credited the testimony of the nurse, who denied placing a necklace on the table, and another staff member, who simply stated that he never saw the necklace in the room during a room sweep. The reasons given for doubting the witnesses' accounts were weak, while the staff members had a clear motivation to deny their involvement. Even if the inferences drawn were correct, however, the failure to include sufficient detail to support these inferences in the investigative record demonstrates that the investigative process is inadequate.

We also saw evidence that the investigations were result-driven and were not a full inquiry into the circumstances that led to the incident or injury. For instance, the individual involved in the pica incident noted above was the subject of two other investigations of pica incidents, and all three were determined to be unsubstantiated. In one of the incidents, the investigator reported to Choate that

“[a]t this point, with no negative outcome for the client, there is no credible evidence.” This suggests that the outcome of the investigation hinged more on whether the individual suffered harm than whether neglect actually took place. This is a troubling approach to investigations, especially in light of the individual’s ongoing pica behaviors, which a detailed investigation may have aided in preventing.

Finally, we observed that investigations at Choate tend to ignore trends in allegations. For example, we noted that, between November 2006 and June 2007, one staff member was alleged to have smothered the faces of three different residents. This is a highly specific allegation, and its repetition by different individuals warranted further investigation. Similarly, during the same time period, another staff member was alleged to have threatened four separate individuals with physical harm, including death, if they did not do as directed. Choate’s apparent failure to detect these trends and perform further inquiry is a significant departure from generally accepted professional standards for investigations.

Choate’s deficient investigative practices undermine its ability to respond to situations of abuse and neglect, and increase the likelihood that harm will continue. Because investigations are not thorough, staff members who may have potentially abused or neglected residents at Choate were permitted to continue interacting with and caring for residents, leading to the potential for future harm. The failure to take adequate steps to prevent this harm violates the constitutional rights of the individuals who reside at Choate.

## 2. Quality Management Is Inadequate

Constitutional requirements and generally accepted professional standards mandate that a facility like Choate develop and maintain an integrated system to monitor and ensure quality of care across all aspects of care and treatment. An effective quality management program must incorporate adequate systems for data capture, retrieval, and statistical analysis to identify and track trends. The program should also include a process for monitoring the effectiveness of corrective actions taken in response to problems that are discovered.

Choate substantially departs from these standards. We found that Choate’s quality management system was highly compartmentalized rather than integrated, and there was a lack of communication among departments. Often, multiple forms must be filled out for the same incident, but they are sent to different departments, increasing the likelihood of discrepancies among the data reported. As discussed earlier in this report, there were significant discrepancies between data reported in the progress notes, clinical records, or external agency notifications and the

individual's and facility's aggregate data. When asked, Choate's quality assurance administrator was unable to explain why these discrepancies existed. The administrator was unable to account for why numerous incidents found in the progress notes or agency notifications were not found in the aggregated data maintained in the quality management department. The inadequacies of the current quality management system have resulted in an environment where harm has occurred without recognition or resolution and will continue to occur if better systems are not put into place.

3. Seclusion and Restraint Usage At Choate Violates Constitutional Standards

Constitutional mandates and generally accepted professional standards require that, in an institution like Choate, restraints only be used when imminent risk of harm to oneself or others is present. Our review of Choate's records indicate that Choate's restraint practices substantially depart from this standard.

Despite recent efforts to reduce use of restraints, Choate continues to use restraints routinely, and often places individuals in four-point and even five-point restraints<sup>4</sup> for unreasonably long periods of time, frequently without ever having attempted to use less intrusive measures. Choate's records indicate that several individuals were restrained in this manner, on average, for more than two and a half hours. Some restraints were much longer; we found examples of individuals who were placed in mechanical restraints for more than six consecutive hours, including:

- A.A., who was restrained for approximately four hours and eight hours, separated by a two hour and 15 minute time of release, in July 2007;
- B.B., who was held in mechanical restraints for seven consecutive hours in December 2006; and
- C.C., who was restrained for nearly six consecutive hours in October 2006.

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<sup>4</sup> In a four-point restraint, an individual is placed on his bed on his back and his wrists and ankles are secured by nylon straps; a five-point restraint includes all the elements of a four-point restraint, with the addition of a strap placed across the individual's chest.

Most egregiously, during his last ten days at Choate before discharge, D.D. was held in four-point or five-point restraints for nine consecutive hours on two occasions, twelve consecutive hours on another occasion, and approximately sixteen consecutive hours on yet another occasion. In total, this individual spent more than 45 hours in restraints during his last ten days at Choate. This high-level of restraint use departs substantially from generally accepted professional standards and violates the restrained individuals' constitutional rights.

### **C. Choate Does Not Provide Adequate Health and Psychiatric Care**

#### **1. Health Care Is Reactive and Uncoordinated**

The Supreme Court has determined that institutionalized persons with developmental disabilities are entitled to adequate medical care. Youngberg v. Romeo, 457 U.S. at 324. The Court labeled this as one of the “essentials of care that the State must provide.” Id. There are many positive aspects of medical care at Choate. In particular, the facility has the benefit of clinically competent, dedicated physicians and nursing leadership. These disciplines, however, are currently not structured in a manner allowing them to be sufficiently responsive to the population they serve, exposing individuals to risk of harm.

Foremost, health care at Choate is reactive rather than forward-looking. Reactive health care occurs when an individual's access to care depends upon the person presenting themselves for assessment and treatment, while proactive health care requires medical professionals to identify individuals at risk, to perform assessments, and to provide appropriate treatment. In a residential disability center setting such as Choate, individuals are often unable to articulate their health status to staff or request medical attention due to intellectual or developmental disabilities. Given these conditions, constitutional mandates require Choate to ensure that the health care provided is sufficiently proactive to identify potential health issues, to intervene before harm or suffering occurs due to illness or injury, and to provide access to health care as soon as possible once symptoms indicating a health problem arise. Regrettably, due to reactive health care delivery, Choate often fails to do enough to identify, assess, treat, and monitor its residents, especially those with complex and high-risk conditions. Choate's provision of reactive medical care undermines the other care and treatment provided at Choate and may unnecessarily prolong individuals' stay at Choate. A.A., discussed in Section II.B.1.b, had 24 injury reports from October 13, 2006 to July 11, 2007, for an average of 2.6 per month. A significant number of these injuries occurred during transfers of A.A. to and from her wheelchair. While Choate responded appropriately to each individual injury when it occurred, we could not find any evidence that her treatment team recognized this high rate of injury and formulated a plan to address it. Only after a fall in July 2007 did A.A.'s physician order all

transfers be performed by two people. Choate's failure to take steps to prevent harm to A.A. is a substantial departure from generally accepted professional standards and violates A.A.'s constitutional rights.

Choate's medical staff primarily utilizes a "sick-call" system to respond medically to individuals once direct care staff or a nurse has identified a resident with symptoms that warrant further assessment by a physician. Once identified as needing a physician's care, Choate residents are typically examined and evaluated by a physician at one of the clinical examination rooms on the facility's campus. Choate's use of clinic-based treatment is standard community practice and is acceptable in a developmental disability center setting. However, this model is not a substitute for methods necessary to ensure that health care providers are adequately monitoring the health status of residents and responding in a timely fashion. In this regard, attending physicians at Choate should also conduct clinical rounds on the residential units to facilitate routine interaction with direct care staff knowledgeable about residents' medical status. Furthermore, clinical rounds would provide attending physicians an opportunity to assess residents in their living environment, where they are likely to learn about and address health related matters with residents before more serious signs of illness occur.

Choate's reactive approach to health care is compounded by the ineffective coordination of health care services at the facility. There is often inadequate collaboration and coordination between and among the various health care disciplines. Failure to coordinate health care appropriately increases the likelihood that health professionals will pursue a course of treatment that may negatively impact another health care provider's treatment and jeopardize the overall care that a resident ultimately receives. Risk to residents is further increased as residents' charts often do not adequately reflect the health care decision-making process or reveal clearly what is happening with residents. Current and future plans of care are difficult to discern from the charts, placing residents at risk of harm because of poor communication and lack of coordination about their care and treatment. The following examples demonstrate the poor communication and lack of coordination in the provision of health care services at Choate, as well as the serious omissions from the medical charts, and emphasize the constitutionally significant harm that can occur from these deficiencies:

- E.E.'s May 2007 monthly review indicates that his neurologist recommended increasing the amount of one medication he received, until he was informed by E.E.'s primary physician that a higher dose of that medication had, in the past, produced ataxia, an inability to control voluntary muscular disorders. This suggests that this information was not in his medical chart, was not in a part of his chart that his neurologist typically would have reviewed, or was not



communicated from one discipline to the other, as his primary physician had clear knowledge of these past effects. Had E.E.'s primary physician not discovered this recommendation, E.E. would likely have suffered further harm. E.E.'s physician's knowledge of E.E.'s medical history is impressive and speaks well of his competence. Nevertheless, a health care system's reliance on an individual's recollection, rather than an accurate, accessible medical record, is inappropriate and unsafe;

- F.F. was found unresponsive in his room on April 14, 2007, and was taken to the local hospital. According to the admitting doctor at the local hospital, his "history is extremely sketchy, most of the information is available from the Emergency Room." This statement strongly suggests that the information Choate provided to the local hospital was inadequate; and
- Similarly, on February 23, 2007, G.G. was admitted to the local hospital for treatment of pneumonia. Her January 25, 2007, Behavior Intervention Plan indicates that she was receiving 500 milligrams of Clozapine, but the admitting note does not indicate that she was on this medication when listing her medications, despite indicating that the admitting doctor had a conversation with her primary physician at Choate. There is no indication in the record that the medication had been discontinued before her admission to the hospital. If this medication was in fact inadvertently discontinued at the time of her admission, she would have gone from receiving a significant dose of the medication to none at all in one 24-hour period.

Other factors also serve to diminish the level of coordinated health care at Choate. For instance, Choate's medical, psychiatric, and psychology staff rely heavily on informal meetings and conversations to relay information about residents' health care status. Unfortunately, in many instances, the underlying facts of these discussions are never recorded as part of the individual's medical history. As a result, Choate health professionals have failed to identify situations where individuals required additional health consultations with other Choate or community-based health care providers. For example, E.E. has an active psychotic disorder and a seizure disorder that have been well-documented for several years. Choate's past trials of antipsychotic medications have produced an increase in seizures, so they were suspended. While the suspension of the trials may be reasonable, it does not appear that Choate professionals have considered obtaining a specific neuropsychiatry consultation to attempt to identify an antipsychotic agent that would not lower his seizure threshold. In our review, we also noted that residents' charts and records often did not contain discharge summaries from

outside hospitals or emergency room visits, and that documentation of discussions with external specialty consultations was inconsistent, ranging from excellent to non-existent. This is a substantial departure from generally accepted professional standards.

These deficiencies in overall medical care place residents at risk, but there is even greater risk for residents in two discrete areas of care: (1) the administration of psychotropic medication; and (2) physical and nutritional management services.

2. Administration of Psychotropic Medication Departs Substantially From Generally Accepted Practices

Psychotropic medications are not dispensed in accordance with generally accepted professional standards at Choate. Constitutional and professional standards dictate that psychotropic medications are prescribed consistent with a documented psychiatric diagnosis and empirically-based evidence of the medications' efficacy. Moreover, psychiatric professionals should record empirically-based evidence of the psychotropic medications' efficacy, along with all attempts to determine the minimum effective dose of the medication for the resident. Without this information, treating professionals are unable to conduct an adequate risk analysis to determine whether the medication's inherent side effects are outweighed by the efficacy of the drug. The inappropriate use of psychotropic medications may undercut the other care and treatment provided at Choate, making it more difficult for the individual to move to a more integrated setting.

During our tour, we discovered that several individuals at Choate were receiving psychotropic medications, including first generation psychotropics, at dosages well-above accepted therapeutic dosages without any empirical evidence of the medications' efficacy or any attempts to identify the medication's minimum effective dose. The medications for the following individuals are illustrative of these problems:

- H.H. has been prescribed 75 milligrams of Haloperidol per day, a much higher dose than is usually utilized. Our review of his records indicated that there is no documentation of psychotic symptoms, and the frequency of his monitored behaviors is low. Moreover, his behavioral difficulties appear to be, in part, secondary to a closed head injury in childhood. Nevertheless, Choate has not made any attempt to decrease the amount of Haloperidol he receives; and
- I.I. was given 50 milligrams of Haloperidol per day until May 3, 2007, at which time her prescription was reduced to 48 milligrams of Haloperidol per day. Our consultant could not find any empirical data

to support this large of a dose of Haloperidol. Indeed, when I.I.'s dose was reduced from 50 milligrams to 48 milligrams, no clinical deterioration appears to have resulted. This suggests that no effort has been made to find the minimum effective dose of Haloperidol for I.I.

These residents are at unjustifiable risk of harm due to excessive and long-term exposure to these medications, including tardive dyskinesia.<sup>5</sup>

We also found a significant diagnostic-therapeutic disconnect at Choate and a lack of detailed documentation in records where the resident's diagnosis does not clearly explain the psychotropic regimen in place. This therapeutic-disconnect results in insufficient explanation or justification in individual records for current and future clinical decision-making. Therefore, the potential harm to residents is two-fold: the person may be treated with inappropriate and/or unnecessary medications and, at the same time, will not receive proper treatment for the underlying mental illness. Similarly, our expert reviewed a number of cases where exemptions from scheduled reductions in antipsychotic medications have been requested and granted absent concurrent empirical evidence that the scheduled reduction in medication would be harmful to the resident. This diagnostic-therapeutic disconnect impairs other aspects of the treatment provided at Choate, unnecessarily prolongs individuals' institutionalization at Choate, and accordingly contributes to violations of the Constitution and Olmstead. The following examples illustrate the diagnostic-therapeutic disconnect present at Choate:

- J.J. was prescribed the psychotropic medications Pimozide, Haloperidol, and Clonazepam, the stated goal for which was to reduce or eliminate symptoms of Tourette's syndrome.<sup>6</sup> According to her records, the dosage of all three of these medications has been increasing, but no empirical evidence of the efficacy of these medications at reducing the severity of the Tourette's disorder is included in her records;

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<sup>5</sup> Tardive dyskinesia is a muscular side effect of anti-psychotic drugs and is primarily characterized by random movements in the tongue, lips, or jaw as well as facial grimacing, movements of arms, legs, fingers, and toes, or even swaying movements of the trunk or hips.

<sup>6</sup> Tourette's syndrome is a neurological disorder characterized by multiple involuntary movements and vocalizations, or tics, which are frequent, repetitive, and rapid.

- K.K. occasionally displays inappropriate behaviors, including, most notably, physical aggression that involves pulling the hair of staff members. He is currently prescribed Perphenazine, a psychotropic medication. According to our consultant's review of his record, however, there is an absence of any description of psychotic symptoms, and there is a notation that a behavior program developed for K.K. in the 1990s was effective in reducing the frequency of the physical aggression and hair pulling. It is therefore not clear that the Perphenazine is being used to treat a psychotic disorder rather than to suppress aggression, which may be occurring on a behavioral basis. Moreover, there is evidence in the record that K.K. has manifested motor side effects that have required treatment with Bzotropine, and that he has also developed dysphagia,<sup>7</sup> potentially related to the Perphenazine;
- L.L. is 44-year-old male who weighed 236 pounds in April 2007, which is 137 percent of his ideal body weight. He is currently on Risperidone, and one of the known side effects of this medication is weight gain. Nevertheless, the section of the record that primarily addresses potential negative side effects focuses primarily on the possible effect on his motor skills. While Risperidone can have some effect on motor skills, the most significant side effects are its metabolic side effects and the potential for weight gain. Especially given L.L.'s obesity, his treatment should at least acknowledge the potential for Risperidone to be exacerbating this problem and consider transitioning him to a more weight-neutral medication. Moreover, the frequency and intensity of his behaviors, as recorded, are not significant enough to bar consideration of a reduction in his Risperidone dosage; and
- M.M. has a long history of violent outbursts, physical aggression, self-injurious behaviors, and inappropriate sexual behaviors. During our review of his records, we found that, although he has been on many different psychotropic medications, it was noted that none of them have been effective at controlling his maladaptive behaviors. We also found no documentation of symptoms related to a psychotic disorder. Nevertheless, M.M. is currently on 600 milligrams of Lithium and 40 milligrams of Haloperidol per day, despite a May 9, 2005, consultation that recommended decreasing the Lithium until discontinued, and a lack of any empirical evidence that the Haloperidol has been helpful, especially at the given dosage, which is higher than usually used.

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<sup>7</sup> Dysphagia is the medical term for difficulty in swallowing.

Furthermore, we could find no documentation in the record that a sustained attempt has been made to determine the lowest effective dose of Haloperidol for M.M.

The continuation of these individuals on psychotropic medications that are not clinically justified by their symptoms, especially in unusually high dosages, or that may be having significant side effects when other medication options have not been attempted, exposes these individuals to unjustifiable risk of harm from the potential side effects inherent in the use of these medications.

During our review, we noted that Choate routinely documents data regarding the frequency of monitored behavioral symptoms. There was no documented evidence, however, that Choate routinely measures the intensity of monitored symptoms. To make appropriate dosage changes and assess the overall efficacy of the psychotropic medication administered, both frequency and intensity must be routinely measured and recorded. In the example of M.M., above, we could only find data on the frequency of his maladaptive behaviors, and none on their intensity.

Finally, as discussed in the previous section, Choate fails to ensure the adequate documentation of interdisciplinary collaborations between psychiatry, psychology, and medicine and here again relies too heavily on informal conversations to relay information necessary for adequate treatment decisions. Choate's psychiatrist and medical doctors indicated during interviews with our consulting expert that extensive discussions between psychiatry and medical occur before psychotropic regimes are implemented or changed. However, the subsequent record review by our expert revealed only infrequent and cursory documentation of these discussions. Furthermore, where discussions and empirical data do exist in the resident's record, this information does not appear to be used to inform the clinical decision-making process on a regular basis.

### 3. Physical and Nutritional Management Are Not Adequately Individualized

Physical and nutritional management services are a significant aspect of adequate health care services for persons with developmental disabilities. These supports should minimize risks associated with swallowing and digestion dysfunctions that predispose an individual to an increased risk of bowel impaction, choking, and aspiration, including aspiration pneumonia. In this area particularly, vulnerable residents need forward-looking care to prevent problems that can lead to illness, hospitalization, and death.

Choate, to its credit, does ensure that some aspects of physical and nutritional management are adequate. Generally accepted professional standards require that Choate assess residents for risk of dysphagia and implement appropriate dietary and programmatic safeguards based on these assessments to prevent the occurrence of harm from swallowing dysfunction. Choate's risk assessments are generally adequate. Barium swallowing studies are consistently conducted by off-ground community providers when initial assessments suggest this is necessary. Further, there is appropriate consultation between the attending physician and speech pathologist to perform initial swallowing evaluations and identify significant swallowing problems that develop in individual residents.

Nevertheless, there are significant deficiencies in Choate's physical and nutritional management, which pose serious risks to residents. Choate does not ensure that appropriate dietary and programmatic safeguards are implemented to prevent the risk of harm from dysphagia. First, the administration of the correct meal to the correct individual relies too heavily on staff recognition of the individual without a back-up system, such as picture cards, to facilitate resident identification. The current system creates the potential for a resident to receive the food tray of another individual in error. During dining, it is imperative that residents receive the correct dining tray to ensure proper nutritional needs are met and to ensure the health and safety of individuals who require foods of a certain texture or consistency.

Second, because Choate employs family-style dining, which normalizes the dining atmosphere, individuals with dysphagia are at greater risk and need to be closely monitored to prevent them from eating too rapidly or from impulsively taking food from another resident's tray. Although many of Choate's residents are currently functioning at a level that does not put them at risk of choking and aspiration, there is a distinct population of individuals whose physical status renders them vulnerable to dysphagia, choking, and aspiration. Choate's meal cards and monitoring plans, however, are not sufficiently individualized for those residents who have empirically-determined risks for dysphagia, choking, and aspiration to provide guidance to staff members on how they should interact with the individual, including interactions such as prompting the individual regarding pacing of food intake. The failure to provide adequately individualized meal plans, along with failure to provide sufficient identification of individuals with meal plans, departs substantially from generally accepted professional standards and places these individuals at risk of harm, including aspiration pneumonia and death, in violation of these individuals' constitutional rights.

#### **D. Choate's Behavioral, Habilitation, and Communication Services Are Deficient**

Choate's residents are entitled to "the minimally adequate training required by the Constitution . . . as may be reasonable in light of [the residents'] liberty interests in safety and freedom from unreasonable restraints." Youngberg, 457 U.S. at 322. The purpose of this training is to enable of the movement of individuals into the most integrated setting appropriate to their needs as required by Olmstead. 527 U.S. at 607. Generally accepted professional standards of care require that appropriate psychological interventions, such as behavior programs and habilitation plans,<sup>8</sup> be used to address significant behavior problems and assist residents to live in more integrated settings. Choate has the benefit of a competent staff of psychologists. However, as of the time of our visit, the facility lacked a chief of psychology and lacked sufficient psychologists to meet the various needs of Choate's residents. Many of the deficiencies addressed below relate to these staffing problems and to the absence of rigorous clinical oversight. In any event, Choate fails in important respects to provide adequate psychology services to meet the needs of its residents.

##### **1. Behavior Programs Are Ineffective**

Use of challenging, even harmful ("maladaptive") behaviors frequently can be an issue for persons with developmental disabilities, and are often one of the reasons the individual is placed 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 learning, in this case, learning effective and healthy ways to meet one's needs and wants.

Indicia that a facility is having difficulty addressing challenging behaviors include high rates of harm to oneself or others, and indicia that a facility lacks adequate behavioral interventions include high rates of restraints and clinically unjustified psychotropic medications. Regrettably, these indicia are present at Choate. The failure to address challenging behaviors adequately inhibits the movement of individuals to a more integrated setting in compliance with Olmstead.

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<sup>8</sup> Habilitation includes, but is not limited to, individualized training, education, and skill acquisition programs developed and implemented by interdisciplinary teams to promote the growth, development, and independence of individuals.

As noted in Section II.C.2, supra, Choate substantially departs from generally accepted professional standards concerning the use of psychotropic medication for individuals with intellectual disabilities. There are a number of individuals at Choate who are receiving dosages of psychotropic medication that are above what are usually thought to be effective therapeutic dosages. There also does not appear to be an attempt to determine minimally effective dosages (“MEDs”) for many of these individuals. Furthermore, our review found a pattern of continuing individuals on high dosages of antipsychotic agents, despite the lack of any empirical evidence that the medication has been helpful.

Similarly, Choate substantially departs from generally accepted professional standards regarding restraint use. As described supra at Section II.B.3, we found numerous instances where individuals were held in mechanical restraints for excessive periods of time, and the manner in which many of the restraints were used, as well as the repeated use of restraints on the same individual, indicate that staff members were unable to respond appropriately to the behaviors that the individual was manifesting.

Further, Choate fails to use appropriate behavioral interventions. Generally accepted professional standards of practice provide that behavioral interventions should be: (1) based upon 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 behavioral interventions increase the likelihood that residents engage in maladaptive behaviors, subjecting them to unnecessarily restrictive interventions and treatments. Choate’s behavioral interventions are often not effective, based on deficiencies that depart from generally accepted professional standards. In particular, they often are not based on adequate assessments, and often are not monitored, evaluated, and revised adequately. The failure to provide adequate behavioral interventions violates these individuals’ constitutional rights and may unnecessarily prolong these individuals’ institutionalization at Choate.

a. Behavioral Assessments Are Inadequate

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. In this regard, 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. Choate's functional assessments are not adequate for this purpose. They do not effectively guide selection of replacement behaviors or intervention procedures, frequently resulting in a weak relationship between assessment results and intervention programs. For example, N.N.'s behavior intervention plan ("BIP") indicates that his "problematic behavior is maintained by him trying to escape<sup>9</sup> staff requests, gaining attention, and access to tangible items." His replacement behaviors are defined as: "Unit Incentive Program," "Empathy Skill," and "Social Skills." On their face, these programs would not teach N.N. how he can escape requests or gain attention or tangibles in more socially acceptable ways. The lack of an adequate behavioral assessment leading to an appropriate behavioral intervention plan to address his maladaptive behaviors inhibits N.N.'s ability to move to a more integrated setting.

Separately, as Choate's policies reflect, it is important to conduct intellectual assessments of individuals at regular intervals. Particularly as persons with developmental disabilities age (especially persons having Down Syndrome) and are exposed to long-term doses of cognition-altering psychotropic medications, their cognitive abilities can change significantly. Such changes affect their habilitation needs, as discussed in Section II.D.2, *infra*, but they also affect their needs for, and the nature of, the behavioral interventions that they receive. Similarly, these assessments are sometimes a requisite for discharge planning. Yet, in practice, Choate is not conducting such assessments when needed. For instance, at the time of our visit, O.O.'s PSP notes that his last intellectual assessment occurred in March of 2002. As of the time of our visit, he was past due for reassessment, according to the policy of the facility and generally accepted professional standards of care. P.P.'s PSP, dated April 19, 2007, notes that his most recent intellectual assessment was on August 15, 2001, which again departs from Choate's policies and generally accepted professional standards. Similarly, the psychometric (i.e., intellectual aptitude) assessment section of Q.Q.'s BIP (dated April 7, 2005, and revised June 14, 2007) indicates that he was last assessed on May 9, 1996. These examples demonstrate Choate's failure to conduct intellectual assessments as necessary.

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

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<sup>9</sup> "Escape" is a term used in psychology to describe certain types of avoidance behavior.

learning objectives and interventions that enable the individual to move to a more integrated setting. 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. Choate's communication assessment inventories reflect an understanding of the linkages between communication and behavior. However, it appears from our review that communication assessments at Choate are performed only infrequently.

Further, where assessments did occur, we found breakdowns in the diagnoses that were subsequently rendered. For instance, the psychometric assessment section of Q.Q.'s BIP (dated April 7, 2005; revised June 14, 2007) indicates that he has a full scale IQ of 58. However, his Axis II diagnoses include "Moderate Mental Retardation," a diagnosis that would require a significantly lower IQ score. Failure to reflect assessment results accurately in Clinical Diagnoses may lead to an inaccurate perception of individuals and inappropriate treatment planning. In this regard, our consultants found a repeated lack of support for psychiatric diagnoses where assessments from psychologists would be warranted. For instance, Q.Q.'s same BIP includes an Axis II diagnosis of personality disorder, NOS (not otherwise specified). The narrative does not offer any justification for this diagnosis, nor does it reference any observable behavioral criteria obviously associated with this psychiatric diagnosis. Interventions premised upon clinically unsupported diagnoses will be effective only by happenstance and easily can be counter-therapeutic, particularly the unwarranted use of psychotropic medication, which is a significant issue at this facility.

b. Behavioral Interventions Are Inappropriate, Insufficient, or Non-Existent

According to generally accepted professional standards, 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 Choate substantially departs from generally accepted professional standards in important respects. As noted above, the facility is relying excessively on psychotropic medications and physical restraints to control behaviors. This is, in part, due to the fact that Choate's behavioral assessments do not lead to effective behavioral interventions, as discussed in the previous section of this letter. Nevertheless, in several instances where assessments, coupled with

observations and record review, pointed to an environmental factor (distinct from mental illness) as the function of a behavior, it appeared that Choate 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, as in the above example of N.N.

Moreover, we found multiple examples of individuals who had been identified as having significant maladaptive behaviors but who nevertheless were not receiving structured behavioral interventions to address these behaviors. For instance, our consultant noted that two individuals on the forensic unit (R.R. and S.S.) were noted to be at risk for self-injurious behavior (“SIB”) but neither had a behavior intervention plan. Further, a treatment team presented data at E.E.’s transition meeting regarding behaviors of “noncompliance,” “property destruction,” “physical aggression,” and “verbal aggression.” Yet, E.E. did not have a behavior intervention plan to address them.

Further, there should be a clinical congruence among targeted behaviors, assessments, and interventions. Yet, we found instances of inconsistency, even as to what an individual’s target maladaptive behaviors were. For instance, N.N.’s behavior improvement plan did not identify the same target behaviors as were listed in his individual education plan (“IEP”). Physical aggression, teasing/provoking, and self-injurious behavior are included on his BIP but not on his IEP.

More fundamentally, we found repeated examples of Choate’s failure to revisit behavioral interventions in response to compelling evidence that an individual’s maladaptive behaviors were not improving, or were even deteriorating. This was true even at mandatory annual reviews that are expressly structured to address such issues. For instance, T.T.’s PSP of February 13, 2007, states that, “[o]verall, [M.] has shown an increase in the frequency or intensity of the target behaviors.” In fact, our review found that all of T.T.’s challenging behaviors for which there was data from the previous year showed an approximately four-fold increase during the first part of the year. Yet, the recommendation was to “[c]ontinue current Behavior Intervention Plan.” Between December 2006 and March 2007, Choate conducted four “Special Program Reviews” for T.T. due to injuries caused by SIB. The facility added interventions consisting of body checks at shift change, one-to-one supervision of T.T. at night, and use of restraints. However, these interventions are focused exclusively on restricting behavior, not modifying it. Significantly, T.T.’s monthly summary reviews for this period stated that the behavior program “[c]ontinues to meet individual’s needs.” Our consultant concluded that, apart from continuing a reduction of this individual’s psychotropic medication, “there was no indication of a team response to his behavioral status.” Additionally, repeated use of restraints at Choate do not lead to meaningful

reassessments of behavioral interventions or to warranted revisions in interventions. Our consultant further opined that, “[t]he failure to revise behavioral intervention plans in response to a lack of progress or to significant events is perhaps the most serious indictment of behavioral treatment at Choate.”

As noted previously, the failure to implement timely and appropriate behavioral interventions undermines the other care and treatment provided at Choate, prolongs these individuals’ use of maladaptive behaviors that led to their institutionalization, and impairs their ability to move to more integrated settings.

c. Implementation of Behavioral Treatment Is Not Documented or Observed

Consistent and correct implementation of appropriate behavioral interventions is essential. Choate uses a “Behavior Drill Procedure,” that “requires that the staff person demonstrate/role play rather than discuss how to implement procedures outlined in the Behavior Drill.” However, it appears that Choate frequently fails to meet this standard. As an initial matter, training records did not reveal which staff should have been trained on BIPs using the Behavior Drill, when the training should have been completed, or which staff have yet to be trained on any given program. Moreover, the facility's practice, as of the time of our review, does not include observation of staff implementing any aspect of the behavior plan. This is a significant deficiency; without relative certainty that plans are being implemented as designed, it is impossible to determine whether a behavioral plan is effective.

d. Monitoring and Evaluation of Behavioral Programs Is Inadequate

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, to avoidable injuries related to untreated behaviors, and to unnecessarily prolonged institutionalization, all in violation of the Constitution and Olmstead.

As a threshold matter, Choate does not assess, for clinical purposes, critical aspects of psychological services at the facility, such as the use of restraints, the use of emergency procedures, the development and update of functional assessments, and staff implementation of programs. There is no systemic tracking and analysis of the type of restrictive components contained in BIPs. In fact, as noted previously, we found several instances of restraint use that were not recorded in Choate's

restraint database. Thus, Choate's current reliance on restraint data for clinical purposes would likely lead to flawed assessments of treatment efficacy on both an individual and a systemic basis.

Further, as noted in Section II.C.2, supra, Choate relies heavily on psychotropic medications as a primary form of behavioral intervention, although it is seeking to reduce the use of psychotropics. As for traditional behavioral interventions, although Choate gathers some data to assess the interventions' efficacy, the facility lacks a standard, clinically justified method to gather data and confirm its accuracy. Additionally, the presence or absence of replacement behaviors, which mitigate or prevent the maladaptive behavior's occurrence, is rarely tracked. In short, Choate lacks a means to ensure that appropriate data are accurately and consistently reported.

Moreover, the BIPs we reviewed failed to provide adequate strategies for measuring the effectiveness of the plan. The outcomes currently emphasized by Choate to measure effectiveness focus on reducing the frequency of problem behaviors but fail to address improving skills or increasing independence adequately so that individuals can be moved to more integrated settings. Although the BIPs all mention collecting data regarding the occurrence of problem behaviors, plans fail to describe clearly, or in some cases to mention, the methods used to promote positive replacement behaviors. Teams routinely fail to monitor data regarding the individual's use of such behaviors.

e. Quality Assurance and Oversight of Behavioral Support Services Are Insufficient

Further, the safeguard of professional review and monitoring of behavior support services, as of our tour, is not taking place at Choate. These responsibilities largely fall on an adequate peer review process (an assessment of a practitioner's work by other professionals in the field to foster compliance with the generally accepted professional standards of the discipline) and a functioning behavior intervention committee ("BIC"). Neither of these important safeguards are functioning at Choate. In particular, we found that the BIC is not appropriately evaluating the content and quality of the behavior programs, or whether they meet professional standards. The BIC's failure to provide critical and substantive review of behavior intervention plans permits behavior programs to continue when these programs are ineffective, inefficient, and inconsistent. The BIC nearly universally approved every plan submitted to it during the time of our review. In particular, after reviewing approximately 120 pages of the BIC's minutes, our consultant did not find any instance where the BIC rejected a BIP, and only found a single instance where the BIC approved a BIP "pending incorporation of required change," although the required change was not identified in the BIC's minutes. We learned

during our visit that the State's chief psychologist for developmental disability services was being dispatched to Choate on an interim basis, in part to address the lack of oversight in Choate's behavioral support services.

Separately, although the behavior intervention process includes an assessment of the individual's rights, our review indicated that restrictive behavioral interventions were being implemented without prior approval from either of Choate's BIC or its Human Rights Committee ("HRC"). We found repeated examples of restrictive interventions that apparently were not subject to such oversight. For instance, O.O. received a "special program review" on

January 5, 2006, at which the treatment team recommended property searches on return from off-grounds activities. Such searches were not included in O.O.'s BIP. Our consultant determined from record review that "there is no indication that they were approved by the BIC or HRC." In fact, our record review did not uncover instances where the HRC provided any substantive review or discussion of restrictive behavioral interventions prior to approving them.

2. Habilitation Programs Do Not Meet Generally Accepted Professional Standards

Persons with developmental disabilities are to receive adequate habilitation training and related vocational and day program services and supports so that they may acquire new skills, grow and develop, and enhance their independence so they can move to more integrated settings. Federal regulations require that:

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

42 C.F.R. § 483.440(a). Choate's habilitation programs do not meet these requirements and are inconsistent with generally accepted professional standards. The failure to provide adequate habilitation programs violates the mandates set forth in Olmstead, 527 U.S. at 607.

As an initial matter, and as noted above, Choate does not conduct cognitive assessments of its residents on a regular basis. Moreover, Choate does not have a coherent method for selecting habilitation learning objectives based on appropriate assessments, and functional and relevant objectives are not being targeted. Our

consultant noted that a great number of the training activities at Choate appear to be nonfunctional, occupying individuals' time but not addressing critical, functional objectives. Specifically, the training objectives at Choate do not appear to address whether the objective facilitates a smoother and more immediate transition to community placement, supports the individual's independent functioning, or improves the individual's quality of life. Similarly, we found PSPs that contained inappropriate goals or objectives when considered in conjunction with other information contained in the PSP. In particular, we found learning objectives that are inappropriate or irrelevant, such as U.U.'s learning objective of identifying his medications, when elsewhere in his PSP it states that he is not currently on any medications. In other PSPs, we found goals and objectives that contradicted the individual's stated or expressed preferences and personal goals. For example, V.V.'s PSP reveals that, from December 2006 to March 2007, a four-month period, he was in a shaving skills program, but V.V. refused to participate because he wanted to keep his facial hair. There is no indication in the PSP that the team questioned the appropriateness of his placement in the program or considered dropping the shaving skills objective. V.V.'s PSP also notes that he continually refuses to work in his vocational program and has, at times, displayed significant disruptive behaviors and "maladaptive behaviors towards peers." The PSP nevertheless concludes that he is appropriately placed in the program without any apparent consideration of alternatives.

Furthermore, individuals at Choate spend little time in habilitation activities. According to the daily activity charts for the first 24 days of July 2007, a review of 49 individuals revealed the following:

- 23 individuals had 10 to 18 days with no activities;
- 23 individuals had 1 day to 9 days with no activities; and
- Only 3 individuals appeared to be involved in activities each of the 24 days.

Training of such infrequency for persons with learning disabilities is not consistent with the requirement of continuous active treatment so that individuals can increase their independence. Moreover, of the habilitation activities provided to these individuals, a large percentage are described as "Music," "Movie," or "News/Weather." These activities are largely passive, and it is unclear how these activities are designed to meet the habilitation needs of the participating individuals. For example, data sheets revealed U.U.'s learning objectives for four weeks yielded a single data sheet indicating that he had "correctly achieved the task" (sorting colored paper from white paper), a total of nine times in the month of June. This suggests that U.U. spends very little time involved in tasks associated

with learning objectives that increase his independence. W.W.'s PSP includes an objective to "describe what activities are occurring in a picture," but it is unclear how this objective aids W.W. in acquiring skills that support independent functioning and facilitate transition to community placement. The failure to provide meaningful habilitation activities on a consistent basis is a substantial departure from generally accepted professional standards. Moreover, Choate's failure to provide adequate active instruction and treatment denies individuals the opportunity to increase their independence and makes community placement difficult.

In addition, the interdisciplinary team does not address whether the amount of training and vocational activity for individuals constitutes adequate active treatment to support an expeditious move to a less restrictive environment, increase independence, and improve quality of life. Nor are there written protocols describing the methodology by which the interdisciplinary team should evaluate and monitor individuals' progress on training objectives. Such analysis is not included in the development and annual review of the PSP. For example, T.T.'s monthly review summaries from October 2006 through May 2007 indicate that no progress was made on any skill over the entire eight month period, but there did not appear to be any effort to alter the programs or address the lack of progress in any fashion. Failure to substantively review development and monitor progress deprives individuals of effective treatment and prevents them from achieving personal goals.

As discussed in Section II.A.1, *supra*, a serious deficiency in the PSPs is the absence of a discharge plan. While Choate identifies barriers to community placement, it does not clearly specify actions the facility should take to overcome those barriers. Generally accepted standards of practice suggest the focus of treatment in a facility should address the barriers that prevent individuals from living successfully in community settings. 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 often will be in a community setting. In fact, generally accepted professional standards of care are increasingly emphasizing use of community settings for skills acquisition. Choate's lack of active instruction, treatment and training in a community setting, coupled with the absence of a discharge plan, greatly hinders success in this area and violates federal law.

### 3. Communication Services Are Not Adequate

If communication skills deteriorate or are not developed, individuals 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 will also make it more difficult for staff to recognize and diagnose health issues, such as pain, and hinders an individual's ability to move into more integrated settings as required by Olmstead. Choate fails to provide its residents with adequate and appropriate communication services and currently lacks the resources to address this deficiency.

More specifically, Choate provides limited speech and language programming to residents. At the time of our visit, we noted a single speech and language pathologist available for the facility, who is also responsible for speech and language services for individuals in the mental health facility. Without an adequate number of full time speech and language pathologists on staff, Choate will continue to provide poor communication services for individuals with developmental disabilities.

In addition, Choate's interdisciplinary collaboration with respect to communication and behavior intervention is relatively weak. Our review suggests that Choate is aware that challenging behaviors can serve as a means of communication. This awareness could provide the basis for interdisciplinary collaboration between speech and language services and behavior support services, but we did not find any evidence that this collaboration was occurring. For example, P.P.'s BIP includes a replacement behavior for inappropriate behaviors that involves prompting him to ask for a break and for preferred items, but his language program instead focuses on receptive identification of common objects. The relationship between the objectives in his behavior program and his language program is unclear, and there is no evidence of collaboration between the two disciplines in producing these plans.

Similarly, we also noted the facility serves individuals with hearing impairments, who are dependent on sign language as their primary form of communication. However, staff on their units were not proficient in sign language or able to communicate effectively with hearing-impaired individuals. Choate's failure to provide consistent access to staff with signing expertise denies these individuals their voice, limits their ability and opportunity to express preferences and choices, and deprives them of an opportunity to participate in their treatment.

#### **E. Choate's Special Education Services For Qualified Students Are Insufficient**

Choate fails to provide sufficient education services to individuals as required by the Individuals with Disabilities Education Act ("IDEA"), 20 U.S.C. § 1401 et seq., Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794, and the

Americans with Disabilities Act, 42 U.S.C. § 12101, et seq. Students eligible for services under the IDEA are required to have an Individualized Education Plan (“IEP”), developed by the responsible education agency, and the IEP must be implemented. 20 U.S.C. § 1414(d). The failure to provide adequate education services also impairs individuals’ ability to move to more integrated settings as required by Olmstead. 527 U.S. at 607.

During our review, we found that certain individuals at Choate, who qualified for special education services and had an IEP in place, were not receiving the services required by the IEP. For example, N.N.'s IEP indicates that Extended School Year services are needed. However, the “Program Schedule” for forensic residents updated on July 19, 2007 indicated that N.N. was not receiving any special education summer services. The failure to ensure that the services required by an individual’s IEP are being implemented violates federal law and departs from generally accepted professional standards.

## **F. Supports, Services, and Planning Are Not Integrated**

Many of Choate’s difficulties in providing adequate supports and services to its residents stem from the facility’s failure to ensure that information is communicated to, and considered by, the disciplines for whom that information is relevant. Persons with developmental disabilities residing in state institutions have a constitutional right to adequate treatment, training, and medical care, Youngberg, 457 U.S. at 315, 319, 322, that is designed to enable an individual to live in the most integrated setting consistent with their needs, Olmstead, 527 U.S. at 607, and a critical aspect of any care and treatment is the integration of information to obtain a holistic understanding of the individual. Without a comprehensive understanding of the person, the services provided to that person are necessarily deficient. Choate does not effectively synthesize information about the individuals it serves in its Personal Service Plans, and the interdisciplinary team process at Choate is inadequate.

### **1. Personal Service Plans Do Not Meet Generally Accepted Professional Standards**

At Choate, the development of a Personal Service Plan (“PSP”) is intended to integrate information about an individual across disciplines. Our review of the PSPs, however, revealed that integration of information is not taking place. The PSPs are not a comprehensive summary of and plan for an individual’s treatment at Choate. The “Summary of Last Year and Current Status” included in the PSPs, while extensive, simply collects reports from individual disciplines, but does not integrate the information from those reports. Moreover, the reports themselves do not reflect collaboration between the disciplines. One example is the PSP of T.T.,

which reports in one section that his challenging behaviors have grown substantially worse over the past year. Nevertheless, the PSP does not include any changes to the Behavior Intervention Plan to address the increasing behaviors, and it also calls for a further reduction of his psychotropic medication without addressing the increasing behaviors. We found another individual with a Behavior Intervention Plan that was not referenced anywhere in his PSP, and thus was not taken into account by other disciplines. Other examples of lack of integration include individuals who are taking psychotropic medications but do not have behavioral intervention programs, and individuals who have personal goals listed in their PSP but have no learning objectives associated with these goals. The failure to integrate information from various disciplines in the PSP undermines the treatment that Choate is attempting to provide and inhibits the ability of Choate's residents to move to more integrated settings.

Our review discovered other omissions from PSPs that substantially depart from generally accepted professional standards. First, we found that, on the whole, PSPs at Choate do not reflect individualized planning. They do not describe the individual's goals, and they contain little information about an individual's personal preferences. Without this information, the PSPs necessarily fail to plan treatment that takes into account the individual's strengths and preferences, as required by generally accepted professional standards. Second, we found that the "Strengths and Needs" section of the PSP lacks a social skills section. This is a troubling omission, as one of the primary reasons individuals reside at Choate is their inability to relate to others in a socially appropriate manner. Third, PSPs lack any section devoted to discharge planning. Generally accepted professional standards dictate that a major focus of an individual's treatment at Choate should be addressing the barriers that prevent the individual from living in the community. The failure to require the inclusion of this information in the PSP is a significant omission.

Finally, PSPs are intended to document an individual's plan of care in language that is understandable to the individual served or their guardian. Indeed, the PSPs at Choate include a specific section entitled "Parents/Guardians Comments" that requires an affirmation by the parent or guardian that he or she "understands and approves the Personal Service Plan." Despite this affirmation in the PSPs at Choate, we found that the PSPs often contained highly technical language and professional jargon that is unlikely to be understood by the individuals or their guardians. Without informed input from individuals and/or their guardians, PSPs will not be what they are intended to be—person-centered.

## 2. Treatment Teams Are Not Integrated

Choate's treatment teams are not integrated across disciplines, resulting in care that does not meet the individuals' needs. This is a substantial departure from generally accepted professional standards.

During our visits, we attended numerous monthly review meetings held by treatment teams for individuals at Choate, and they were uniformly characterized by a lack of collaboration across disciplines. Moreover, the summaries of those meetings consistently fail to document an interdisciplinary approach to the challenges an individual presents, as well as any substantive team discussion about those challenges. For example, O.O. had a target behavior added to his behavior intervention plan on January 18, 2007, but the summary of the monthly review meeting for January 2007 does not include any discussion of the behavior or provide any rationale for adding it as a target behavior. V.V.'s monthly review summaries for August through November 2006, a four-month period, contained no evidence that any discussion was taking place by the team regarding his Money Skills and Vocational Skills programs. In each of the four summaries, the only included language regarding his progress in these programs was: "He is currently working on a money objective. He will continue to work on this objective." and he "is working on a vocational program. He will continue to work on this program." A more egregious example is that of T.T., who had multiple injuries due to self-injurious behaviors from December 2006 through March 2007. The injuries triggered four Special Program reviews, but the summaries of the monthly review meetings for January, February, and March 2007 all indicate that the behavior program "continues to meet individual's needs." The failure to exchange information adequately and integrate that information into meaningful treatment is a substantial, and very significant, departure from generally accepted professional standards. Furthermore, without accurate and complete documentation of the interdisciplinary team process, it is impossible to evaluate treatment teams' actions and build upon successful interventions.

We also found the monthly review meetings and summaries had several significant omissions. One troubling omission was the lack of action plans that were developed through the monthly review process. None of the monthly review meetings that we attended while at Choate produced any action plans to address an individual's needs, and the monthly review summaries that we reviewed routinely failed to include any action plans. A second omission that we observed was the failure to review and discuss restraint data during monthly reviews meetings. We found several examples where a restraint occurred during the time period for the monthly review, but the monthly review summary did not make any reference to the restraint, nor was there any documentation of whether the team had considered whether changes to the active treatment plan were necessary to prevent the need

for further restraints. A third omission in the monthly review process was a routine failure to address discharge planning and barriers to placement. The monthly review meetings we attended did not include any substantive discussion of discharge planning or barriers to placement in the community, and the monthly review summaries we reviewed similarly failed to address these issues. These omissions diminish Choate's ability to provide adequate treatment to its residents.

Choate also fails to include critical individuals in the interdisciplinary team process. We found that direct care staff are not included in team meetings, undermining the team process. Direct care staff provide information based on direct observations of the individual that is critical to effective treatment planning. The failure to involve direct care staff in treatment decisions also undercuts Choate's ability to ensure that consensus is reached on appropriate treatment and that treatment is uniformly implemented. Additionally, we found that the individuals themselves are not consistently present at monthly review meetings. At least four individuals - X.X., G.G., Y.Y., and Z.Z. - did not attend their monthly review meetings during our visit. We do note, and appreciate, that when individuals were present at meetings, effort was made to engage them actively in their treatment and the individuals were treated with dignity and respect. Nevertheless, generally accepted professional standards dictate that an individual be actively involved in their treatment planning, and effort should be made to ensure that individuals are more consistently involved in this process.

### **III. MINIMUM REMEDIAL MEASURES**

To remedy the identified deficiencies and protect the constitutional and statutory rights of Choate residents, the State should promptly implement, at a minimum, the remedial measures set forth below. Many of these deficiencies could be remedied, in part, by focusing the care and treatment at Choate on moving individuals into the most integrated settings appropriate to their needs:

#### **A. Transition and Discharge Planning**

1. Ensure that each individual residing in Choate is served in the most integrated setting appropriate to meet each person's individualized needs. To this end, the facility should take these steps:
  - a. Provide transition, discharge, and community placement services consistent with generally accepted professional standards of care to all individuals residing at Choate;
  - b. Actively pursue the appropriate discharge of individuals residing at Choate and provide them with adequate and

appropriate protections, supports, and services, consistent with each person's individualized needs, in the most integrated setting in which they can be reasonably accommodated, and where the individual does not object;

- c. Set forth in reasonable detail a written transition plan specifying the particular protections, supports, and services that each individual will or may need in order to safely and successfully transition to and live in the community;
- d. Develop each transition plan using person-centered planning principles. Each transition plan should specify with particularity the individualized protections, supports, and services needed to meet the needs and preferences of the individual in the alternative community setting, including their scope, frequency, and duration. Each transition plan should include all individually-necessary protections, supports, and services, including but not limited to:
  - i. housing and residential services;
  - ii. transportation;
  - iii. staffing;
  - iv. health care and other professional services;
  - v. specialty health care services;
  - vi. therapy services;
  - vii. psychological, behavioral, and psychiatric services;
  - viii. communication and mobility supports;
  - ix. programming, vocational, and employment supports; and
  - x. assistance with activities of daily living.
- e. Include in each transition plan specific details about which particular community providers, including residential, health care, and program providers, can furnish needed protections, services, and supports;

- f. Emphasize the placement of residents into smaller community homes in its transition planning;
- g. Avoid placing residents into nursing homes or other institutional settings whenever possible in its transition planning;
- h. Identify in each transition plan the date the transition can occur, as well as timeframes for completion of needed steps to effect the transition. Each transition plan should include the name of the person or entity responsible for:
  - i. commencing transition planning;
  - ii. identifying community providers and other protections, supports, and services;
  - iii. connecting the resident with community providers; and
  - iv. assisting in transition activities as necessary.

The responsible person or entity shall be experienced and capable of performing these functions.

- i. Develop each transition plan sufficiently prior to potential discharge so as to enable the careful development and implementation of needed actions to occur before, during, and after the transition. This should include identifying and overcoming, whenever possible, any barriers to transition. Choate should work closely with pertinent community agencies so that the protections, supports, and services that the individual needs are developed and in place at the alternate site prior to the individual's discharge;
- j. Update the transition plans as needed throughout the planning and transition process based on new information and/or developments;
- k. Attempt to locate community alternatives in regions based upon the presence of persons significant to the individual, including parents, siblings, other relatives, or close friends, where such efforts are consistent with the individual's desires;

- l. Provide as many individual on-site and overnight visits to various proposed residential placement sites in the community as are appropriate and needed to ensure that the placement ultimately selected is, and will be, adequate and appropriate to meet the needs of each individual. Choate should modify the transition plans, as needed, based on these community visits;
- m. Establish in each individual transition plan a schedule for monitoring visits to the new residence to assess whether the ongoing needs of the individual are being met. Each plan should specify more regular visits in the days and weeks after any initial placement;
- n. Ensure that each individual residing at Choate be involved in the team evaluation, decision-making, and planning process to the maximum extent practicable, using whatever communication method he or she prefers;
- o. Use person-centered planning principles at every stage of the process. This should facilitate the identification of the individual's specific interests, goals, likes and dislikes, abilities and strengths, as well as deficits and support needs;
- p. Give each individual residing at Choate the opportunity to express a choice regarding placement. Choate should provide individuals with choice counseling to help each individual make an informed choice and provide enhanced counseling to those individuals who have lived at Choate for many years;
- q. If any individual residing at Choate opposes placement, Choate should document the steps taken to ensure that any individual objection is an informed one. Choate should set forth and implement individualized strategies to address concerns and objections to placement;
- r. Educate individuals residing at Choate about the community and various community living options open to them on a routine basis;
- s. Provide each individual with several viable placement alternatives to consider whenever possible. Choate should provide field trips to these viable community sites and facilitate



overnight stays at certain of the community residences, where appropriate;

- t. Provide ongoing educational opportunities to family members and/or guardians with regard to placement and programming alternatives and options, when family members and/or guardians have reservations about community placement. These educational opportunities should include information about how the individual may have viable options other than living with the family members and/or guardians once discharged from Choate. Choate should identify and address the concerns of family members and/or guardians with regard to community placement. Choate should encourage family members and/or guardians to participate, whenever possible, in individuals' on-site, community home field trips;
- u. In coordination with the State, develop and implement a system, including service coordination services, to effectively monitor community-based placements and programs to ensure that they are developed in accordance with the individualized transition plans set forth above, and that the individuals placed are provided with the protections, services, and supports they need. These and other monitoring and oversight mechanisms should serve to help protect individuals from abuse, neglect, and mistreatment in their community residential and other programs. The State's oversight shall include regular inspections of community residential and program sites; regular face-to-face meetings with residents and staff; and in-depth reviews of treatment records, incident/injury data, key-indicator performance data, and other provider records;
- v. Serve individuals who are placed in the community with an adequate number of service coordinators to meet individuals' needs. The State's service coordination program should provide for various levels of follow-up and intervention, including more intensive service coordination for those individuals leaving Choate with more complex needs. To encourage frequent individual contact, individuals leaving Choate should be served by service coordinators who carry a caseload of no more than 25 individuals at a time. Service coordinators involved with individuals from Choate with more complex and intensive needs will carry a caseload of no more than 20 individuals at a time.

All service coordinators should receive appropriate and adequate supervision and competency-based training;

- w. Provide prompt and effective support and intervention services post-placement to residents who present adjustment problems related to the transition process such that each individual may stay in his or her community residence when appropriate, or be placed in a different, adequate, and appropriate community setting as soon as possible. These services may include, but not be limited to:
  - i. providing heightened and enhanced service coordination to the individual/home;
  - ii. providing professional consultation, expert assistance, training, or other technical assistance to the individual/home;
  - iii. providing short-term supplemental staffing and/or other assistance at the home as long as the problem exists; and
  - iv. developing and implementing other community residential alternative solutions for the individual.
- x. Regularly review various community providers and programs to identify gaps and weaknesses, as well as areas of highest demand, to provide information for comprehensive planning, administration, resource-targeting, and implementing needed remedies. The State should develop and implement effective strategies to any gaps or weaknesses or issues identified.

## **B. Protection From Harm**

- 1. Provide incident, risk, and quality management services consistent with generally accepted professional standards to all residents at Choate. To this end, the facility should take these steps:
  - a. Ensure that residents are supervised adequately by trained staff and that residents are kept reasonably safe and protected from harm and risk of harm;
  - b. Develop and implement adequate policies and procedures regarding timely and complete incident reporting and the

conduct of investigations of serious incidents. Train staff and investigators fully on how to implement these policies and procedures. Centrally track and analyze trends of incidents and injuries so as to develop and implement remedial measures that will prevent future events. Include systemic recommendations in investigation reports and ensure the prompt implementation of remedial measures to prevent future occurrence of incidents and injuries; and

- c. Develop and implement mechanisms to ensure that, when serious incidents such as allegations of abuse, neglect, and/or serious injury occur, Choate staff take immediate and appropriate action to protect the individuals involved, including removing alleged perpetrators from direct contact with individuals pending either the investigation's outcome or at least a well-supported, preliminary assessment that the employee poses no risk to individuals or the integrity of the investigation.
2. Ensure that any device or procedure that restricts, limits, or directs a resident's freedom of movement (including, but not limited to, mechanical restraints, physical or manual restraints, or chemical restraints) be used only in accordance with generally accepted professional standards. To this end, the facility should take the following steps:
    - a. Ensure that restrictive interventions or restraints, including seclusion, are never used as punishment, in lieu of training programs, or for the convenience of staff. Ensure that only the least restrictive restraint techniques necessary are utilized, and that restraint use is minimized;
    - b. Develop and implement a protocol that places appropriate limits on the use of all restraints, especially the use of physical holds and one-point, two-point, three-point, four-point, and five-point restraints, as well as the routine use of chemical restraints; and
    - c. Ensure that ineffective behavior programs that may contribute to the use of restraints are modified or replaced in a timely manner. For those individuals subjected to chronic use of restraint associated with difficult behavior problems, obtain outside expertise to help the facility address the persons'

behavior problems in an attempt to reduce both the behaviors and the use of restraint.

### **C. Health and Psychiatric Care**

1. Provide medical care, nursing, and therapy services consistent with generally accepted professional standards to residents who need such services. To this end, the facility should take these steps:
  - a. Provide each resident with proactive, coordinated, and collaborative health care and therapy planning and treatment based on his or her individualized needs;
  - b. Develop and implement an adequate system that ensures timely, accurate, and thorough recording of all medical care provided to each resident including consultation with outside medical providers, emergency room visits, and hospitalizations; and
  - c. Establish an effective physical and nutritional management program for residents who are at risk for aspiration or dysphagia, including but not limited to the development and implementation of assessments, risk assessments, interventions for mealtimes and other activities involving swallowing, and monitoring to ensure that interventions are effective. Ensure that staff with responsibilities for residents at risk for aspiration and dysphagia have successfully completed competency-based training commensurate with their responsibilities.
  
2. Provide psychiatric services consistent with generally accepted professional standards to residents who need such services. To this end, the facility should take these steps:
  - a. Ensure that each resident with mental illness is provided with a comprehensive psychiatric assessment, a DSM-IV diagnosis, appropriate psychiatric treatment including appropriate medication at the minimum effective dose that fits the diagnosis, and regular and ongoing monitoring of psychiatric treatments to ensure that it is meeting the needs of each person. Ensure that psychiatrist(s) provide new assessments and/or revisions to any aspect of the treatment regimen whenever appropriate. Ensure that quality behavioral and other data is provided to psychiatrists in making their assessments. Ensure

that psychiatric services are implemented in close collaboration with facility psychologists and others such, when warranted, to provide coordinated behavioral care; and

- b. Ensure that psychotropic medication is only used in accordance with generally accepted professional standards and that it is not used for punishment, in lieu of a training program, for behavior control, in lieu of a psychiatric or neuropsychiatric diagnosis, or for the convenience of staff. Ensure that no resident receives psychotropic medication without an accompanying behavior program.

#### **D. Behavioral, Habilitation, and Communication Services**

1. Provide residents with training, including behavioral and habilitative services, consistent with generally accepted professional standards to residents who need such services. These services should be developed by qualified professionals consistent with accepted professional standards to reduce or eliminate risks to personal safety, to reduce or eliminate unreasonable use of bodily restraints, to prevent regression, and to facilitate the growth, development, and independence of every resident. To this end, the facility should take the following steps:
  - a. Procure adequate psychology staffing and hours to meet the needs of the residents, including adequate leadership and oversight of psychological services;
  - b. Provide residents who have behavior problems with an adequate functional assessment so as to determine the appropriate treatments and interventions for each person. Ensure that this assessment is interdisciplinary and incorporates medical and other unaddressed conditions that may contribute to a resident's behavior;
  - c. Develop and implement comprehensive, individualized behavior programs for the residents who need them. Through competency-based training, train the appropriate staff how to implement the behavior programs and ensure that they are implemented consistently and effectively. Record appropriate behavioral data and notes with regard to the resident's progress on the programs;

- d. Monitor adequately the residents' progress on the programs and revise the programs when necessary to ensure that residents' behavioral needs are being met. Provide ongoing training for staff whenever a revision is required;
  - e. Ensure that all residents receive meaningful habilitation daily. Ensure that there is a comprehensive, interdisciplinary habilitative plan for each resident for the provision of such training, services and supports, formulated by a qualified interdisciplinary team that identifies individuals' strengths, needs, preferences, and interests. Ensure that the plans address the residents' needs, preferences, and interests in an integrated fashion that utilizes the individuals' existing strengths. Ensure that staff are trained in how to implement the written plans and that the plans are implemented properly; and
  - f. Provide an assessment of all residents and develop and implement plans based on these assessments to ensure that residents are receiving vocational and/or day programming services in the most integrated setting appropriate to meet their needs. Ensure that there is sufficient staffing and transportation to enable residents to work off campus or attend off-campus programming or activities when necessary.
2. Provide communication services consistent with generally accepted professional standards to residents who need such services. To this end, the facility should take these steps:
    - a. Procure adequate staffing and hours of speech and language services to meet the needs of residents; and
    - b. Ensure that speech and language services are developed and implemented in collaboration with facility psychologists and other services to provide coordinated care.

## **E. Special Education Services**

1. Provide education and special education services consistent with generally accepted professional standards to residents who need such services. To this end, the facility should develop and implement IEPs consistent with the requirements of the IDEA.

## **F. Integrated Supports, Services, and Planning**

1. Provide supports, services, and planning that are integrated across disciplines, consistent with generally accepted professional standards, to all residents at Choate. To this end, the facility should take these steps:
  - a. Ensure that PSPs integrate information across disciplines and reflect collaboration among disciplines. Ensure that PSPs demonstrate individualized planning, including the individual's needs, strengths, goals, and preferences. Develop and implement PSPs that include a section on transition and discharge planning, including the barriers to community placement and the facility's plan to address those barriers. Ensure that PSPs are understandable to the individual served or their guardian; and
  - b. Ensure that interdisciplinary and treatment team meetings integrate information across disciplines and reflect collaboration between disciplines, and that the integration and collaboration is appropriately documented. Ensure that individuals necessary to obtaining a comprehensive understanding of the resident, including direct care staff and the individual who is the subject of the meeting or their guardian, are included in the interdisciplinary team process. Ensure that action plans are developed and implemented to address the needs and/or issues identified in those meetings, including but not limited to inappropriate behaviors or use of restraint. Ensure that transition and discharge planning, including barriers to placement, are routinely discussed at team meetings.

#### IV. CONCLUSION

We appreciate the cooperation we received from the Illinois Department of Human Services and the State's Attorney General's Office. We also wish to thank the administration and staff at Choate for their professional conduct, their generally timely responses to our information requests, and the extensive assistance they provided during our tours. Further, we wish especially to thank those individual facility staff members, both new and longstanding, who make daily efforts to provide appropriate care and treatment, and who improve the lives of residents at Choate. Those efforts were noted and appreciated by the Department of Justice and our expert consultants.

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

Please note that this findings letter is a public document. It will be posted on the website of the Civil Rights Division. 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 our website until 10 calendar days from the date of this letter.

Provided that our cooperative relationship continues, we will forward our expert consultants' reports under separate cover. These reports are not public documents. Although our expert consultants' reports are their work – and do not necessarily represent the official conclusions of the Department of Justice – their observations, analyses, and recommendations provide further elaboration of the issues discussed in this letter and offer practical technical assistance in addressing them. We hope that you will give this information careful consideration and that it will assist in your efforts at promptly remediating areas that require attention.

We are obliged by statute to advise you that, in the unexpected event that we are unable to reach a resolution regarding our concerns, the Attorney General is empowered to initiate a lawsuit, pursuant to CRIPA, to correct deficiencies of the kind identified in this letter, 49 days after appropriate officials have been notified of them. 42 U.S.C. § 1997b(a)(1). We would prefer, however, to resolve this matter by working cooperatively with you. We have every confidence that we will be able to



do so in this case. The lawyers assigned to this matter will be contacting your attorneys to discuss next steps 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,

Thomas E. Perez  
Assistant Attorney General

cc: The Honorable Lisa Madigan  
Illinois Attorney General  
Office of the Attorney General of Illinois

The Honorable Michelle R.B. Saddler  
Secretary  
Illinois Department of Human Services

Mary-Lisa Sullivan, Esq.  
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The Honorable A. Courtney Cox  
United States Attorney  
Southern District of Illinois