U.S. Department of Justice
Civil Rights Division

JS:TDM:KKD:dj
DJ 168-23-36

Special Litigation Section - PHB
950 Pennsylvania Ave, NW
Washington DC 20530

July 27, 2011

BY FIRST-CLASS AND ELECTRONIC MAIL

Mary-Lisa Sullivan
General Counsel
Illinois Department of Human Services
100 West Randolph, Suite 6-400
Chicago, IL 60601

RE: *Investigation of Choate and Howe Developmental Centers*

Dear Ms. Sullivan:

We write to follow up on our call of July 7, 2011 regarding the United States' investigations of the Clyde L. Choate Mental Health and Developmental Center ("Choate") and the former W.A. Howe Developmental Center ("Howe").

As we discussed, given the lapse in time since we issued our letters of finding in November 2009, in order to better assess the current status with regard to conditions at Choate and to get a better understanding about how Choate, and formerly Howe, fit into the State's system for serving individuals in the most integrated setting pursuant to Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12132 et. seq., we request that the State provide us with the documents listed below. To the extent possible, we would appreciate that the documents be provided in electronic format.

1. The current census of Choate, including each individual's name, date of birth, date of admission, and housing unit.

2. A list of all individuals who have been discharged from Choate since November 1, 2009, including each individual's name, date of birth, date of admission, former Choate housing unit, current address, current community provider (if applicable) and type of residential setting to which the individual was discharged such as nursing facility, private ICF/DD, group home (list size if possible), State-operated developmental center, family home, or own apartment or house.

3. A list of all individuals at Choate who have died since November 1, 2009.

4. A list of all individuals admitted to Choate since November 1, 2009.

5. A list of all individuals currently at Choate who have been identified as able to be served in a more integrated setting.

6. A list of all individuals currently at Choate who have, or whose guardian has, expressed an interest in or objected to transitioning to a more integrated setting.

7. Documents related to the community placement preferences of individuals identified in document request numbers 5 and 6.

8. Documents related to the assessment and transition/discharge plans for individuals identified in document request numbers 5 and 6.

9. All documents relating to services or information provided to individuals at Choate and/or their guardians to assist them in making an informed choice about moving to a more integrated setting.

10. All documents relating to criteria for admission to Choate.

11. All reports, analyses, recommendation studies or other documents completed after November 1, 2009 regarding the admission of individuals with developmental disabilities into Choate and other State-operated developmental centers.

12. A description and all documents related to the method by which the State pays Choate, including a description of what services are included in a per diem or bundled rate and what services are billed separately. For all cost data, delineate the State portion of the cost and the federal portion of the cost.

13. All documents related to the cost of housing and serving individuals at Choate. For all cost data, delineate the State portion of the cost and the federal portion of the cost.

14. Documents from November 1, 2009 to the present sufficient to show the annual average, median, and high and low range of yearly Medicaid and Medicare expenditures for services provided to individuals in Choate.

15. All documents related to the budget for Choate for FY 2009, FY 2010, and FY 2011.

16. All current Choate policies, procedures, guidelines, and corresponding screening forms (blank) pertaining to the assessment, transition, and placement of individuals at Choate to another residential setting.

17. A current organizational chart for Choate, identifying staff names and position titles.

18. All reports, surveys, reviews, audits, and quality assurance evaluations, analyses, or critiques relating to the treatment or care of Choate residents prepared by any internal or external group or committee, including but not limited to surveys, reviews, and investigations conducted by the Centers for Medicare and Medicaid Services, and any plans of correction or responses to any of these reports, reviews, surveys, evaluations, analyses, and critiques.

19. All reports, analyses, recommendations, studies or other documents completed after June 1, 2009 related to discharging individuals from Howe and closure of the facility.

20. A list of the individuals who were discharged from Howe since June 1, 2009, including each individual's name, date of birth, date of admission, former Howe housing unit, current address, current community provider (if applicable) and type of residential setting to which the individual was discharged such as nursing facility, private ICF/DD, group home (list size if possible), State-operated developmental center, family home, or own apartment or home.

21. A list of the individuals who were discharged from Howe to a more integrated setting since June 1, 2009 who have since been admitted to another State-operated developmental center or nursing home, including each individual's name, date of birth, date of admission, former Howe housing unit, former community provider, and current housing unit.

22. All reports, analyses, recommendations, studies or other documents related to quality management regarding the current placement of individuals discharged from Howe since June 1, 2009.

23. A description of all categories of community-based services and housing available to persons with developmental disabilities served in the State's system, including a description of the services in the State's Home and Community-Based Waiver (HCBS waiver).

24. Documents related to any cost limitations for any services or housing identified in document request number 23. For all cost data, delineate the State portion of the cost and the federal portion of the cost.

25. Documents outlining the eligibility criteria for services or housing identified in request number 23.

26. Documents identifying the number of individuals currently on any waiting lists for services or housing identified in request number 23, the amount of time each individual has been waiting, and the expected wait time to receive the services or housing identified in request number 23.

27. All documents related to any emergency, urgent, or priority eligibility criteria for services or housing identified in request number 23.

28. All reports, analyses, recommendations, studies or other documents related to the quality management system regarding the community-based services and housing available to persons with developmental disabilities served in the State's system since November 1, 2009.

29. Documents related to the State's budget for community-based services for individuals with developmental disabilities, including HCBS waivers, for FY 2009, FY 2010, and FY 2011.

30. Documents from November 1, 2009 to the present sufficient to show the annual average, median, and high and low range of yearly Medicaid and Medicare expenditures for services provided to individuals residing in settings other than Choate or the other State-operated developmental centers.

31. Documents submitted to CMS regarding the HCBS waiver since November 1, 2009.

32. All reports, analyses, recommendations, studies or other documents completed after November 1, 2009 related to transitioning individuals from Choate and other State developmental centers into the community.

33. A copy of the State's current *Olmstead* Plan and any prior versions or updates to the plan since July 2006.

34. Documents related to the development of the State's *Olmstead* Plan, including any financial analyses conducted in developing the plan.

35. Documents related to the implementation of the State's *Olmstead* Plan, including any financial analyses developed regarding the number of individuals to be discharged from developmental centers in FY 2009, FY 2010, and FY 2011.

36. Any documents relating to budget cuts affecting the implementation of the State's *Olmstead* Plan.

37. All documents concerning any analysis or comparison of the cost of serving individuals in Choate or any other State-operated developmental center and the cost of serving individuals with developmental disabilities in the community, including through the HCBS waiver.

38. Any documents or agreements specifically limiting the State's ability to close any State-operated developmental center.

39. Documents sufficient to show the total annual census of all the State-operated developmental centers from January 1, 2005 to the present.

40. A list of the individuals who were discharged from the other seven State-operated developmental centers since January 1, 2009, including each individual's name, date of birth, date of admission, former housing unit, current address, current community provider (if applicable) and type of residential setting to which the individual was discharged such as nursing facility, private ICF/DD, group home (list size if possible), State-operated developmental center, family home, or own apartment or home.

41. A list of all individuals currently at the other seven State-operated developmental centers who have been identified as able to be served in a more integrated setting.

42. A list of all individuals currently at the other seven State-operated developmental centers who have, or whose guardian has, expressed an interest in or objected to transitioning to a more integrated setting.

43. Documents related to any policies or practices regarding assessing and offering community based alternatives to individuals seeking admission to the State-operated developmental centers.

44. Documents related to any policies or practices regarding identifying individuals in the State-operated developmental centers for possible transition into a more integrated settings.

45. Documents related to any policies or practices regarding discharge planning for individuals in the State-operated developmental center s to more integrated settings.

Thank you for your time and consideration. We would like to speak with you to discuss these document requests and facilitate the State's ability to respond in the most appropriate manner. We can be available for a call at your convenience. If you have any questions, please do not hesitate to call me at (202) 514-1841.

Sincerely,

Kerry Krentler Dean
Attorney
Special Litigation Section

U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General *Washington, D.C. 20530*

NOV 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.[1] 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.

---

[1] 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,"[2] 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.

---

[2] 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.,[3] 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

---

[3] 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[4] 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.

[4] 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.[5]

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.[6] 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;

---

[5] 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.

[6] 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 Benztropine, and that he has also developed dysphagia,[7] 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.

---

[7] 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,[8] 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.

---

[8] 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[9] 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

---

[9] "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. Morever, 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.
General Counsel
Illinois Department of Human Services

Lilia Teninty, Director
Illinois Department of Human Services
Division of Developmental Disabilities

Jan Farmer, Director
Clyde L. Choate Developmental Center

The Honorable A. Courtney Cox
United States Attorney
Southern District of Illinois

U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General *Washington, D.C. 20530*

NOV 19 2009

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

Re: Investigation of the W.A. Howe Developmental Center, Tinley Park, Illinois

Dear Governor Quinn:

We are writing to report the findings of the investigation of the Civil Rights Division and the United States Attorney's Office for the Northern District of Illinois of conditions and practices at the W.A. Howe Developmental Center ("Howe"), in Tinley Park, Illinois. On July 25, 2007, we notified you of our intent to conduct an investigation of Howe pursuant to the Civil Rights of Institutionalized Persons Act ("CRIPA"), 42 U.S.C. § 1997. CRIPA authorizes the Department of Justice 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 December 3-7, 2007, we conducted an on-site review of care and treatment at Howe with expert consultants in various disciplines. Before, during, and after our tour, we reviewed a wide variety of relevant State and facility documents, including policies and procedures, as well as medical and other records relating to the care and treatment of Howe residents. During our tour, we also interviewed Howe administrators, professionals, staff, and consultants, and visited residents in their residences, at activity areas, and during meals. 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 presentations at the close of our on-site review.

We would like to express our appreciation to Howe administrators, professionals, and staff, as well as to the State officials involved in our investigation, for their assistance, cooperation, professionalism, and courtesy throughout our investigation. We hope to continue to work with the State and Howe officials in the same cooperative manner going forward.

We have concluded that numerous conditions and practices at Howe violate the constitutional and federal statutory rights of its residents. Many of the findings we make in this letter are due to or exacerbated by Howe's failure to focus its treatment and care on moving individuals into the most integrated settings appropriate to their needs. In particular, we find that Howe fails to provide its residents with adequate: (1) protection from harm; (2) health care; (3) psychiatric care; (4) behavioral treatment and habilitation; (5) integrated treatment planning; and (6) transition planning and placement in the most integrated setting. See Youngberg v. Romeo, 457 U.S. 307 (1982); Title XIX of the Social Security Act, 42 U.S.C. § 1396; 42 C.F.R. Part 483, Subpart I (Medicaid Program Provisions); Americans with Disabilities Act ("ADA"); 42 U.S.C. § 12132 et seq.; 28 C.F.R. § 35.130(d); see also Olmstead v. L.C., 527 U.S. 581 (1999).

We are aware that, on September 5, 2008, the State announced its intention to close Howe by June 30, 2009. We are furthermore aware that the State temporarily halted closure planning earlier this year, before announcing on August 28, 2009, its final decision to close Howe, and to complete all resident transitions by April 2010. While the Department of Justice acknowledges the State's closure deliberations and decision, the purpose of this letter is advise you formally, in accordance with CRIPA, of the findings of our investigation, the facts supporting them, and the minimum remedial measures necessary to remedy the deficiencies set forth below. 42 U.S.C. § 1997b(a). Even as the closure of Howe proceeds, the constitutional violations at the facility will have continuing effects, for which the State must provide relief in whatever setting a Howe resident eventually resides. As it closes Howe, the State retains a statutory obligation to move the facility's residents to the most integrated setting appropriate for them as individuals.

I. BACKGROUND

Located in Tinley Park, Illinois, approximately 30 miles outside of Chicago, Howe is a licensed 500-bed intermediate care facility for individuals with developmental disabilities. Howe is one of nine residential developmental centers operated by the Illinois Department of Human Services. At the time of our tour in December 2007, Howe housed 349 adult residents. The Howe campus consists of 40 residential group homes, 35 of which were occupied during our tour. Most of the group homes housed between 8 and 11 individuals. The campus also includes an

administration building, a professional services building, and a social habilitation building.

In 2006, the U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services ("CMS") placed Howe in "immediate jeopardy" of losing Medicaid certification due to serious deficiencies identified at the facility by CMS surveyors.[1] In 2007, prior to our investigation, CMS terminated Howe's Medicaid contract. At the time of the termination, Medicaid funding provided approximately one-half of Howe's $53 million annual budget. To date, Howe remains decertified.

In addition to the deficiencies identified by CMS, several prominent statewide disability advocacy organizations in Illinois expressed concern over the quality of care provided to the residents at Howe. These organizations routinely cited to a number of resident deaths during 2005-2007, alleging substandard care as a contributing factor to those deaths. At the time we notified the State in July 2007 of our investigation, at least fourteen residents had died in the previous 18 months. Since our tour in December 2007, sixteen more residents have died.

This is the second CRIPA investigation of Howe undertaken by the Department of Justice. In 1992, after a multi-year investigation of Howe, we entered into a consent decree with the State of Illinois regarding necessary improvements to the facility. The consent decree, filed in the United States District Court for the Northern District of Illinois, specifically required Howe to make improvements in the areas of resident assessment, evaluation, and training; use of restraints; medical care; medication administration; record keeping; and staffing. In 1996, we stipulated to an agreed order to terminate the consent decree and dismiss the case. Unfortunately, we received substantial allegations of new or continuing violations and therefore, as noted above, opened a new CRIPA investigation in 2007. This letter provides our findings from the current investigation.

II. FINDINGS

A. TRANSITION PLANNING

Federal law requires that a state actively pursue the timely discharge of institutionalized residents to the most integrated, appropriate setting that is consistent with the resident's needs. Howe is failing to place residents in the most

---

[1] CMS surveys are conducted by a designated State Survey Agency ("SSA"). The SSA in Illinois is the Illinois Department of Public Health ("IDPH").

integrated setting appropriate to their individual needs, in violation of Title II of the Americans with Disabilities Act ("ADA"), and the regulations promulgated thereunder. In construing the anti-discrimination provision contained in Title II of the ADA, the Supreme Court has held that "[u]njustified [institutional] isolation . . . is properly regarded as discrimination based on disability." Olmstead v. L.C., 527 U.S. 581, 597, 600 (1999). Specifically, the Court established that states are required to provide community-based services and supports for persons with developmental disabilities when the state's treatment professionals have determined that community placement is appropriate, provided that the transfer is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with disabilities. Id. at 602, 607.

Successful transition of residents into a more integrated setting is a fundamental obligation of an institution such as Howe. Howe's failure to meet this obligation is caused in part by the breakdowns in care noted in the below sections of this letter. The State's decision to close Howe does not relieve the State from its obligation to provide federally mandated adequate transition planning. To the contrary, the State's decision to close Howe intensifies the facility's poor record of successful transitions. Howe's deficiencies detailed below – to protect residents from harm (section B), provide adequate health care (section C), psychiatric care (section D), behavioral treatment and habilitation (section E), and integrated treatment planning (section F) – all hinder the residents' opportunities to live in a more integrated setting and unnecessarily prolong institutionalization.

The result of Howe's failure to move residents to community placements is to deprive residents of the most integrated appropriate treatment setting, to exacerbate challenging behaviors, and to foster institutionalized behaviors and attitudes. Among the staff at Howe, we observed a culture that accepts movement toward community placements at a glacial pace. Often there is no movement at all. Transition to community placement, when considered, is viewed as a distant possibility.

Of the residents present at Howe for some portion of the period between September 1, 2006, and September 30, 2007, only 80 residents were recommended for placement by their treatment team. Although persons with disabilities can live in community-based settings with proper supports, fewer than one-fourth of the individuals at Howe were recommended for community placement by their treatment team. During this same 13-month period, only 32 residents (approximately 9% of the census at the time of our tour) were discharged to community placements. This rate of community placement is low and results in a large number of individuals remaining at the facility for long periods of time.

For example, B.L., a resident who has no challenging behaviors, no psychiatric symptoms, can dress herself, complete all morning grooming, eating, and bedmaking activities before leaving for her workshop placement, and has few health problems, was not referred to any community agencies in the past year. This failure clearly maintains B.L. in an overly restrictive setting and deprives her of meaningful choices about where to live.

According to Howe's list entitled, "People Recommended for Community Placement by Treatment Team - 9/1/06 - 9/30/07," residents recommended for placement in the community in 2004 still have not been placed. Of residents who have requested community placement, some have remained at Howe even longer, despite evidence that there is no serious obstacle to such movement. For example, B.M., whose "one issue is his anger," had anger management replacement behavior consistently above 90 percent and, at times 100 percent, for the last 11 of 14 months. Although there is also a note about B.M. having mobility problems, B.M.'s ISP does not even address steps toward community placement.

Staff at Howe hold incorrect beliefs as to prerequisites for community living, which further restricts residents' progress toward living in a less restrictive setting. For example, staff expressed to our expert consultant the belief that residents needed to be successful in a community day program before actively pursuing community living. Further, staff consider success in the development of social, vocational, and basic living skills to be requirements for community placements, which they are not. Those skills increase residents' options for living in the community, but social deficits, vocational deficits, and basic living deficits are not inherently barriers to community living. Staff also expressed the belief that a failure to develop certain skills necessitates postponing target dates for placement by a matter of years. For example, A.A.'s Qualitative Monthly Review Summary acknowledges that he has the goal of moving into a community placement, but states that "at the pace he is going[,] the target dates may need to go up a few years." (Emphasis added).

As barriers to placement are not identified in ISPs, and there are no goals aimed at overcoming those barriers, the transition process is simply not a focus for staff. Where goals regarding placement are included, they are vaguely stated and monitoring information is obscure. Sometimes the goals rely on external agencies or outside persons to move the process forward. For example, C.P.'s ISP states that her goal of moving to a community-based residence was not met "due to guardian's lack of interest and knowledge to seek placement at this time."

Transition plans, when generated at all, come too late and lack sufficient information to generate useful, proactive planning. Too often, the section entitled, "What will make this person successful in community living environment?" is blank.

Transition plans are not included in residents' records, so they are not readily available to the treatment team.

We did note that, once a resident is referred, the process becomes more proactive and effective. This was evidenced by the fact that, at the time of our tour, placements had increased. Nevertheless, Howe residents are institutionalized far longer than necessary due to deficient transition planning. This deficiency is of great concern as Howe proceeds with closure plans and transitions residents to new settings.

B. PROTECTION 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 v. Romeo, 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, the State of Illinois fails to protect Howe residents from harm and risk of harm, and to provide residents with a reasonably safe living environment. Failure to provide a reasonably safe living environment undermines the other care and treatment provided at Howe, prolongs the time periods spent by individuals there, and delays the movement of individuals to more integrated settings in violation of Olmstead.

Generally accepted professional standards to protect persons with developmental disabilities from harm in an institutional setting, which are necessary to prevent constitutional violations, utilize a two-pronged approach: (1) identifying and responding quickly to occurrences of harm by collecting pertinent information, and (2) implementing affirmative measures to effectively manage the risk of future occurrences of harm. The processes of responding to and preventing harm are generally understood as "incident management" and "risk management" respectively.

1. Incident and Risk Management

The term "incident management" can be understood as the immediate responses taken by the facility when an individual has incurred actual harm or wherein the proclivity for such harm is real and/or imminent. Although Howe maintains an Incident Management Committee to review reportable incidents and injuries, as explained in further detail below, individuals at Howe are at significant risk of harm and injury due to the facility's ineffective incident management.

Additionally, generally accepted professional standards for facilities like Howe require implementation of a risk management system that identifies an individual's risks of harm and develops preventative interventions through skill acquisition, environmental changes, and therapeutic interventions. Interdisciplinary treatment teams must thoroughly assess residents to determine individual risks and develop effective strategic interventions to reduce risk. Moreover, facilities must utilize objective data to measure the success of the strategic interventions in preventing harm, and when necessary modify the interventions to improve outcomes.

We find that Howe's risk management practices do not provide the level of protection necessary to reasonably prevent harm, substantially depart from generally accepted professional standards, and consequently fail to meet constitutional and federal standards. Howe residents continue to be at significant risk of harm and injury due to the facility's absent or ineffective responses to ongoing harm. Below, we discuss three areas of incident and risk management: (1) reportable incidents and injuries; (2) risk assessment and intervention; and (3) abuse and neglect investigations.

a. Reportable Incidents and Injuries

Generally accepted professional standards require that facilities like Howe maintain a reporting system to identify all reportable incidents and injuries accurately and responsibly. A "reportable" incident will commonly include incidents such as falls, peer aggression, accidents, restraints, self-injurious behaviors, injuries of unknown origin, and abuse and neglect allegations.

To its credit, Howe's criteria for collecting reportable incident information appears to align with generally acceptable standards. Howe's procedures for actually reporting and reviewing these incidents, however, substantially depart from those standards. Indeed, the procedures have not been revised for nearly 20 years. More troubling than the procedures being simply outdated is our finding that there are significant inconsistencies in the staff's adherence to the procedures. These inconsistencies result in under-reporting of reportable incidents, which in turn, results in insufficient responses to occurrences of harm.

Despite the evidence of under-reporting, the number of reportable incidents at Howe is disturbing. For example, for the period of September 2006 through September 2007, Howe reported nearly 3,000 incidents, including 8 deaths and more than 100 allegations of abuse and neglect. Many of these incidents describe harm suffered by individual residents that could have been avoided had the facility taken preventive measures to manage the risk of harm.

Our expert consultant concluded that among the types of reportable incidents, aggression and assault are "rampant" at Howe. From September 2006 to September 2007, more than 150 individuals – about half of all residents at the facility – were assaulted by their peers. The injuries suffered as a result of these aggressive incidents included: scratches, abrasions, human bites, head trauma, and in more than 20 instances, lacerations that required the use of staples, sutures, or Dermabond[2] to close the wounds. Human bites alone account for 25 percent of all aggressive incidents at Howe, a trend that our expert consultant found to be "staggering" in comparison with other institutions with similar populations.

Other notable examples of reportable incidents of harm during the period of September 2006 through September 2007 included residents who suffer from pica[3] successfully obtaining and ingesting foreign objects such as mechanical restraint devices, plastic bags, keys, metal coils, and puzzle pieces, as well as some 22 individuals who reportedly sustained fractures, including one resident who suffered three fractures, and three residents who had two fractures.

Many Howe residents suffered significant personal injury during the occurrences of reportable incidents of harm. For example:

- In June 2007, A.A.[4] displayed increasingly intense aggressive behavior until he punched through a window with his hand and arm. He required 23 sutures at the local emergency room to close the wound.

- In July 2007, when a Howe physician referred B.B. to the local hospital due to her coughing and respiratory distress, x-rays identified three rib fractures. Investigators concluded that she may have suffered the fractures when she tripped over a misplaced chair the previous day. At the time of the fall, however, staff reported only that her foot was sore.

---

[2] Dermabond is the brand name of a liquid bonding agent used as an alternative to stitches for closing wounds.

[3] Pica is a medical condition in which a person ingests or attempts to ingest nonfood substances such as clay, chalk, hair, or glue.

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

- Similarly, in October 2007, staff found C.C. with significant bruising on her shoulder and back, and reported that she "may have fallen from her bed or chair." Twenty-two hours later, a Howe physician examined C.C. and sent her to the local hospital for x-rays. There, the emergency room physician diagnosed a fractured clavicle, and reported the matter to the Illinois State Police because the physician concluded that it was hard to believe that her injury came from a fall.

Alarmingly, 7 of the 10 most frequently injured residents had been assigned intensive staffing at the time of their injuries. The intervention strategy of assigning enhanced individual supervision for a time after injuries occur, as we saw at Howe, is often ineffective to ensure residents' daily safety. For example, during the period of September 2006 through September 2007:

- Tragically, D.D. suffered significant injuries while on 1:1 supervision,[5] prior to his unexpected death in April 2007. These injuries included multiple lacerations requiring 40 sutures, injuries to his face and head, human bites to his chest, and an abrasion to his penis requiring closure with Dermabond. When the frequency of harm to D.D. escalated in late 2006, strategies to protect him remained relatively unchanged. His record reflects that substantive changes were limited to psychoactive medication adjustments and the cancellation of his daily program schedule.

- E.E. suffered 37 injuries while on 1:1 supervision, including a fracture in September 2006, and lacerations requiring Dermabond on January 19, January 26, and February 23, 2007.

- F.F. injured himself on at least 40 separate occasions while on intensive supervision during the one-year period examined. Some injuries were so severe as to require treatment at a hospital, including the need for sutures or Dermabond on at least four occasions.

- G.G. had an intensive staffing assignment during the one-year period reviewed until her unexpected death in November 2007. Yet during this time, G.G. sustained at least 25 injuries, including two self-inflicted lacerations requiring closure by Dermabond.

---

[5] The term "1:1 supervision" refers to a heightened level of supervision in which the facility will order a staff person to continually supervise one particular resident.

- Similarly, H.H. was placed on 1:1 supervision in November 2001 due to her unsteady gait and risk of falling. Yet from September 2006 through November 2007, H.H. suffered 28 injuries, including two lacerations in July 2007 requiring closure by Dermabond.

- I.I. was placed on 1:1 supervision nearly 10 years ago to prevent him from intentionally harming himself. Despite the heightened supervision level, I.I. caused injury to himself 13 times in the one-year period examined.

In addition to the reportable incidents identified by Howe, we are concerned, as stated above, about the problem of under-reporting of incidents of harm. Howe does not have a firm grasp on the actual numbers of reportable incidents, injuries, and uses of restraints[6] at the facility. The pervasive (and self-admitted) under-reporting of incidents of harm at Howe minimizes the extent of the actual harm occurring, which in turn results in insufficient responses to the occurrences of harm to residents. In a review of Acute Care Logs for just one week, we found more than twenty instances of injury to residents that were treated by medical staff but had not been reported on either the individual's injury history or the facility's aggregate injury totals. These omissions included serious injuries such as head injuries, fractures, and lacerations requiring sutures and staples.

Compilation of accurate information regarding occurrences of harm is a critical first step in maintaining an adequate incident management system. On the basis of our examination, Howe falls substantially short of accepted standards of practice in reporting incidents and compiling data regarding resident harm. This dereliction has contributed to violations of residents' constitutional rights.

b. Risk Assessment and Intervention

Howe has not implemented policies or procedures to identify and reduce risk of harm to residents. The Risk Management Committee, Howe's primary vehicle for managing risk, does not address resident risks from a systemic standpoint. Rather, the committee limits its focus to strategies to reduce enhanced staffing assignments to individuals currently assigned intensive staffing. Our expert consultant found that "for all intents and purposes, [Howe] had no formal risk management system as late as December 2007."

---

[6] The use of restraints at Howe is discussed below in section II.D.2 of this letter.

Effective risk management requires that assessments and intervention strategies be taken prior to harm whenever possible, yet Howe only identifies residents at risk of harm after the occurrence of actual harm. This practice underscores Howe's lack of prevention efforts, which leads to constitutionally inadequate protection of residents.

Although Howe has identified some residents at risk of harm, even if that identification only happened after the actual occurrence of harm, Howe fails to identify residents at risk of harming others. In some cases, Howe has failed to identify such residents even after the occurrence of actual harm. The following residents, among many others, were not identified as being at risk of harming others despite the serious and recurring injuries they inflicted on their peers:

- J.J. injured peers on four occasions between October 2006 and August 2007. When J.J. pushed K.K. out of her wheelchair, she caused K.K. to fracture her maxillary spine. Three days after the incident with K.K., J.J. struck and injured L.L.

- M.M. assaulted N.N. in October and December 2006, and January 2007. The latter assault caused N.N. a laceration deep enough to require sutures.

- O.O. injured five peers on six separate occasions from November 2006 to June 2007, including an assault on P.P., and a laceration to Q.Q. requiring sutures.

- From October 2006 through July 2007, R.R. attacked and injured S.S. four times, and injured three other peers at least once.

- T.T. injured seven different individuals, causing bite wounds on at least two occasions, during the one-year period of September 2006 through September 2007.

- In November 2006, U.U. assaulted V.V., causing a laceration requiring sutures to close. The following month, U.U. assaulted W.W., causing a laceration that required staples to close.

Howe's failure to provide adequate intervention to address residents' aggressive behaviors places residents at continued risk of serious harm and substantially departs from generally accepted professional standards.

Additionally, although we note that Howe opened a special residence to safely house women with pica just prior to our tour in December 2007, many ingestion

hazards remained evident, including metal shower curtain rings, dried and plastic flowers, and stereo speaker wires. Though preventive measures at this residence are a good starting point, additional steps must be implemented to reduce opportunities to engage in pica.

c. Abuse and Neglect Investigations

Based on extensive record and mortality reviews, we find that abuse and neglect of residents is pervasive at Howe. This conclusion is consistent with the findings of CMS and the State's protection and advocacy organization. The facility investigated approximately 100 allegations of abuse and neglect in the year ending in September 2007. Nearly 75 percent of those incidents alleged physical or sexual abuse. Based on our review, Howe's system to investigate alleged harm is not sufficient to hold accountable those who engage in abuse and neglect, and thus promotes constitutional violations.

Generally accepted professional standards for investigative practices require that investigations be timely, thorough, and logical. The extent to which an investigation is thorough is measured in part by the degree to which the investigator probes for answers, researches facility documents, and challenges discrepant accounts of events. This includes gathering all relevant evidence, and interviewing and re-interviewing witnesses. Logical investigative conclusions are reached when the investigator is able to apply critical thinking to the information he or she has gathered, and synthesize that information into a coherent report.

The overall quality of Howe's investigations falls substantially below generally accepted professional standards because investigations fail to reach logical, well-reasoned conclusions. In some instances, the investigative files were in such disarray that it was difficult, if not impossible, to discern the process and outcome of the investigation. The disorganized manner in which the investigative records are maintained at Howe reflects the disorganized and incomplete quality of the investigations themselves.

Of the 100 abuse and neglect investigations Howe initiated[7] from September 2006 to September 2007, only six were substantiated, while the outcomes of 43 others were not indicated on facility reports. The two examples presented below

---

[7] Illinois' Office of Inspector General ("OIG") also conducts investigations of alleged abuse and neglect at state-operated facilities for individuals with developmental disabilities. We do not address those investigations in this Findings Letter.

from the period examined illustrate Howe's lack of thoroughness in conducting abuse and neglect investigations:

- The investigation of X.X.'s sudden death in July 2007 revealed that two attending staff members failed to provide cardiopulmonary resuscitation ("CPR") after finding X.X. unresponsive in his bed because the staff members simply "did not think to do it." Reportedly, when a staff member found X.X. unresponsive, lying face down in his bed, she unsuccessfully attempted to wake him. She then allegedly yelled for another staff member to call an emergency code. Reportedly, instead of immediately calling the code, the staff member ran to the room and attempted to wake X.X. without success. The staff member then allegedly reported the incident to the facility operator, who in turn paged the nurse. When one of the staff members later told the investigator that she had tried to obtain a CPR facial mask for X.X., the investigator did not probe further to find out why she was looking for a CPR mask when she stated previously that she "did not think" to initiate CPR. The lack of critical thinking applied during this investigation may have exonerated staff negligence that may have contributed to X.X.'s death. More troubling, we found evidence in this matter that indicated Howe records may have been falsified, because bed check notes for X.X. were entered after he went to the local hospital. The administrative review of the investigation does not indicate that document falsification was identified or addressed.

- The investigation of alleged verbal abuse by a staff member, who was watching television while on duty, had obvious flaws. In October 2007, two family members were in a residence retrieving the personal belongings of their brother who had recently died. When entering the home the family members allegedly saw a staff member sitting alone in the living room watching television. Reportedly, while in the brother's room, the family members heard the staff member verbally abuse a resident in an effort to make the resident stop what he was doing and sit down. The investigators of this incident, however, failed to interview the alleged victim, other residents in the area at the time of the alleged abuse, or the alleged perpetrator's peers or supervisors. Moreover, the investigation failed to address why a staff member was sitting alone watching television while she was on duty. After the alleged perpetrator simply denied the allegation and a second employee denied hearing anything at all, Howe investigators determined that there was insufficient evidence to support the allegation and closed the investigation.

Based on our review of Howe investigations over a twelve-month period, we find that Howe's inadequate investigative practices must improve significantly to meet the constitutional rights of the individuals who live at Howe.

2. Quality and Records Management

Generally accepted professional standards require that a facility like Howe 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.

Additionally, generally accepted professional standards in record documentation require that an institution's official record be an accurate and thorough account of the care of the resident, allowing access to the individual's most current medical, behavioral, social, and habilitative information. Failure to keep the record in a timely, organized fashion compromises the integrity of the record and provides an opportunity for erroneous clinical decision-making by treatment teams.

a. Quality Management

Howe substantially departs from generally accepted quality management standards. Howe conducts a biannual injury analysis that is largely dependent upon staff providing timely information, which often does not occur. Because the necessary information is not timely provided, the injury analysis is completed months after injury trends occur. With such extensive delays, it is virtually impossible to identify and address significant current trends. As a result, we find that Howe's process for quality management falls substantially short of meeting generally accepted professional standards.

b. Records Management

In each of our record reviews, both on-site and after our tour, we found significant deviations from generally accepted professional standards. For example, we saw illegible entries by numerous staff; progress notes placed in the record out of order; and outdated assessments and support plans. According to our expert consultant, the records at Howe are "maintained haphazardly at best." Howe's failure to maintain a generally acceptable documentation system poses significant risks for its residents, and promotes constitutional violations.

3. Use of Restraints

Generally accepted professional standards and constitutional mandates require staff to release a resident from physical and mechanical restraints when he or she no longer presents an imminent threat to him/herself or others. Moreover, restraints are only to be used in the presence of imminent danger, and the level of intrusiveness of the restraint is to be graduated with the least restrictive manner necessary to prevent harm. For example, if a resident begins to show aggression toward another person, but ceases the aggressive behavior after being restrained, then the threat of imminent harm to self and others is eliminated, and the restraint must be released.

Restraint practices at Howe deviate substantially from generally accepted professional standards, specifically in the facility's use of four, five, and six-point restraints. Residents at Howe are subject to such restraints too frequently and for too long. From September 2006 to September 2007, Howe staff placed more than 700 restraints on residents. Many of these restraints were applied consecutively, resulting in individuals being restrained for hours at a time. For example, residents Y.Y., Z.Z., A.B., J.J., A.D., and F.F. spent between three and eight hours at a time in restraints. In 60 percent of Howe's uses of restraints, residents were immobilized with their wrists and ankles strapped in place. In many cases, individuals were also strapped across their chests (five-point restraint) and placed in a helmet or face-mask (six-point restraint).

Moreover, Howe's procedures to review the appropriateness of restraint were frequently untimely and cursory. Examples of inappropriate restraint use at Howe include:

- Staff placed resident D.D., who died suddenly in February 2007, in four, five, and six-point restraints with increasing frequency during the last months of his life. Staff mechanically restrained D.D. on nine occasions between October and December 2006, despite serious health concerns regarding his hypertension and erratic behavior. On November 29, 2006, D.D. was mechanically restrained for two hours without evidence that his vital signs were checked at all. On December 4 and 10, 2006, when staff again mechanically restrained D.D. for two hours, his blood pressure rose to 138/90 and 190/120, respectively. On December 29, 2006, when D.D. was again mechanically restrained, the nurse contacted the Howe physician, reported elevated pulse and blood pressure (180/100) readings, yet the physician did not order D.D.'s release from the restraints. Ninety minutes later, D.D.'s blood pressure reached 200/100 while still in five-

point restraints, and staff finally released him and gave him hypertension medication.

- In March 2007, A.B. became upset when her sweater zipper broke; staff personally held her for five minutes, and then placed her in five-point restraints for 35 minutes. When documenting what justified this intrusive response, staff wrote that A.B. "began [hitting] self on hand. Blocking, verbal prompt did not stop the behavior." The psychologist and Qualified Mental Retardation Professional ("QMRP") reviewed this restraint more than 40 days later, but noted that no changes were needed to the resident's behavior program.

- In October 2007, when staff told A.B. to stop picking her teeth, she began to yell and hit her face. When verbal prompts and physical blocks of her arms were unsuccessful in stopping the self-injurious behavior, staff physically held A.B. for ten minutes, and then placed her in five-point restraints for 55 minutes. The QMRP reviewed the restraint two weeks later and concluded that the resident's behavior intervention plan remained appropriate.

Howe's indiscriminate use of restraints, and untimely and cursory reviews of whether they are appropriate, constitute an unlawful deprivation of residents' constitutionally protected liberty interests.

C. HEALTH CARE

The Supreme Court has determined that institutionalized persons with developmental disabilities are entitled to adequate health 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. Identifying a resident's health care needs and providing adequate health care is a basic component of the planning necessary for an individual to live in the most integrated setting appropriate to the individual's needs. Failure to provide adequate health care undermines the other care and treatment provided at Howe and may unnecessarily prolong individuals' stay at Howe.

Plainly stated, the health care provided to Howe residents is inadequate, falling well below constitutional and other federal standards. Timely access to necessary medical care often is dangerously delayed. Medical assessments occur too infrequently, the documentation of medical charts is lacking, and effective communication between medical providers is absent. These deficiencies have resulted in residents experiencing worsening of symptoms, progression of illnesses, and death.

Health care at Howe 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 foward-looking 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 Howe, individuals are often unable to articulate their health status to staff or request medical attention due to intellectual or developmental disabilities. Given these conditions, it is incumbent upon Howe 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. Below, we address eleven areas of health care we find to be problematic at Howe.

1. General Medical Care

Among the generally accepted professional standards of care in developmental facilities like Howe is the requirement that access to necessary medical care be timely. Delays in assessments, progress reporting, and treatment put residents at risk of experiencing complications and avoidable suffering. We found numerous examples of delays in residents receiving necessary medical care, and observed that there are no clear standards or expectations for the Howe medical staff regarding the frequency of physician assessments and progress reporting. These problems have led to violations of the Constitution.

While monthly physician progress notes appeared to be the standard in the past, our expert consultant's review of Howe's medical charts revealed that this was not the practice during the period of September 2006 through September 2007. Some medical charts showed gaps of three to five months between physician progress notes, while several others showed gaps as large as seven to eight months. The examples below illustrate Howe's problems regarding delayed access to necessary medical care and infrequent physician assessments and progress reporting:

- The medical chart of X.X., a 30-year-old resident who died in July 2007, contained a physician progress note and order dated April 6, 2007, requesting a neurological consultation. The medical chart does not indicate, however, that any consultation ever took place in the three months prior to X.X.'s death. According to the autopsy report, the cause of X.X.'s death was "seizure disorder, secondary to congenital

hydrocephalus/natural."[8] According to Howe's medical records, X.X. was last examined by a neurologist on January 20, 2005, more than two years earlier. A note in his medical record on February 2, 2007, reported bizarre behavior including, "spitting in shoes and inside his pants, urinating on the floor . . . was redirected; told to stop and also blocked . . . will continue to observe and monitor throughout the day." Numerous other notes indicated inappropriate urination, which can be suggestive of worsening hydrocephalus, yet this behavior was not recognized as potentially reflecting a worsening medical condition. Further, there is an eight-month gap in physician progress notes from August 2006 through April 2007. Not only did X.X. not see a neurologist in a timely manner, but the only medication prescribed to him was a cream to treat dry skin.

- A.E. died in July 2007 from hydrocephalus. The last physician progress note was entered into A.E.'s medical chart more than a month before her death, and her last physical examination was in January 2007. There is no record of neurological consultation, and the documentation for her physical examination noted that no neurological exam was completed at that time, except for checking deep tendon reflexes. Moreover, A.E.'s vital signs were occasionally not recorded, and at times when her vital signs were poor, there was no documentation of pulse oximetry[9] results.

- A.F. is a resident with chronic active Hepatitis C. A.F.'s medical chart indicates that in January 2006, it was recommended that a liver ultrasound exam be completed. The ultrasound did not occur, however, until 15 months later, in April 2007. An assessment in July 2007 recommended a colonoscopy and an esophagogastroduodenoscopy

---

[8] Hydrocephalus is an abnormal condition in which cerebrospinal fluid accumulates in the ventricles of the brain because of blockage of normal fluid outflow from the brain or failure of fluid to be absorbed into the bloodstream quickly enough.

[9] Pulse oximetry is a noninvasive diagnostic test used for detecting oxygen levels in the blood.

("EGD"),[10] but at the time of our tour in December 2007, some five months later, we saw no evidence that either test had been completed.

These examples also indicate, in particular, that the medical staff at Howe do not provide ongoing assessments of residents' neurological problems, which is exacerbated by the fact that there is no on-site neurology service at the Howe clinic. Residents must be transported to a hospital approximately one hour away. The time from referral to appointment ranged from one to three months to see the neurologist. This dramatically limited the continuity of care and overall involvement of neurologists in resident care. In two of the examples noted above, residents died from complications associated with hydrocephalus, a serious, yet manageable condition. Hydrocephalus can be fatal in cases when the diagnosis is not early, and the symptoms are not regularly monitored and appropriately treated. If treated early and appropriately, however, individuals with hydrocephalus can recover with a good quality of life.

Additionally, generally accepted professional standards require that there be effective communication between medical providers and specialists in order to ensure that findings and recommendations are addressed. A review of Howe's medical charts reveals that consultation reports do not show when, or if, the primary treating physician reviewed the results of the consultation.

The lack of effective communication and sharing of information between multiple medical providers working with the same patient can result in delays in treatment, duplication of treatment, and complications due to conflicting approaches to care. In some cases, the breakdown in communication results in tragedy, as illustrated below:

- In February 2007, C.D. died of a heart attack. On the day she died, C.D. underwent an unscheduled gynecological exam without the necessary anti-anxiety medication she typically received prior to gynecological exams, mammograms, and dental visits. Witness accounts of the exam describe C.D., who was blind and non-verbal, as being extremely upset, restrained by staff, and repositioned frequently during the exam. C.D.'s medical chart indicates that she was sensitive and resistant to touch, and contains a "desensitization plan" to reduce

---

[10] An EGD is a diagnostic procedure in which an endoscope (a long, flexible, lighted tube with an attached videocamera) is guided down a patient's mouth, throat, esophagus, stomach, and duodenum (the beginning of the upper intestine). The endoscope allows a physician to visually detect abnormalities in the organs of the upper gastrointestinal tract.

anxiety during medical examinations, which includes the administration of anti-anxiety medication. In fact, her medical record documented successful procedures, including mammograms, when the plan was closely followed, as well as prior unsuccessful procedures conducted without the benefit of sedation. C.D.'s medical chart did not reveal any documented urgent or emergent need for the gynecological exam to be conducted that day, nor was there any documentation that the interdisciplinary team or primary care physician approved the departure from C.D.'s desensitization plan. The lack of communication and coordination regarding C.D.'s exam resulted in her undergoing an unnecessary and avoidable traumatic procedure. Eyewitnesses to the exam reported that C.D. constantly struggled during the procedure and was held down by several staff members. The resulting effects on her heart rate, blood pressure, and other sympathetic nervous system responses potentially contributed to her fatal arrhythmia.

While we address C.D.'s tragic death as an example of Howe's ineffective communication between medical providers, we are compelled to note also the glaring inconsistencies in the documentation of this incident. Particularly troubling in this regard is the physician's note for the procedure itself; the note omits any mention of any problems with cooperation or agitation by C.D. The discharge transfer summary completed after C.D.'s death is similarly silent regarding the struggle of her exam, indicating only that C.D. "was undergoing a medical procedure, had a heart attack, and was provided life-saving services and rushed to the hospital." It was only in a CMS survey conducted shortly after C.D.'s death that the facts surrounding C.D.'s extreme agitation during the procedure are first documented.

Generally, we have found that the primary focus of the medical care provided at Howe is acute care. This type of "reactive" approach to providing medical care accounts for Howe's poor record of assessments, progress reporting, and communication. Our expert consultant's review of Howe's medical charts did not locate any efforts directed at providing preventative care, routine screening, or holistic treatment of Howe's developmentally disabled residents. Although we observed that physicians at Howe were able to verbally provide detailed summaries of residents' acute medical issues during medical staffing meetings and when visiting residents, irregular physician evaluations or assessments that only address an acute need in isolation from the complete individual increases the risk of overlooking important information that affects care and the residents' quality of life. For example:

- A.A.'s medical chart shows regular monthly physician progress notes until April 2006, at which point the notes appear only in regard to

acute issues. Those notes make no mention of A.A.'s bipolar disorder, and the sleep record in the chart is from 2005, with no information for 2006 or 2007. Individuals diagnosed with bipolar disorder should have ongoing monitoring of sleep patterns in order to detect the emergence of hypomania/mania as early as possible. In A.A.'s case, this monitoring did not occur, or at least was not provided to the physician; the physician progress notes are reactive to acute issues, and do not regularly track the status of A.A.'s overall health.

- Howe's Assessment Initial/Annual Comprehensive Physical Exam form adds to the facility's lack of individualized and continuous care, as the form contains pre-populated responses for the treating physician to check. This form prevents a truly individualized assessment and increases the risk that a physician reviewing the chart will assume that incomplete areas of the form mean that the findings were normal.

2. Medical Emergencies

The medical emergency response system at Howe falls substantially below generally accepted professional standards and places residents at risk of suffering serious complications or death. Howe staff is slow to recognize medical emergencies, and is often disorganized in its response. Moreover, information concerning medical emergencies, including follow-up documentation and incident reporting, is often incomplete, disorganized, and untimely. In some cases, the reports are simply inaccurate and misleading. Competency-based training with regard to medical emergencies is also inadequate. This is problematic in cases where a physician is not present during the emergency, because a direct care staff or an unskilled nurse will have to delay providing emergency treatment until a skilled nurse, an Emergency Medical Technician, or a physician arrives. This delay of potentially critical treatment places residents at risk of severe injury or even death. The following are just a few tragic examples of Howe's ineffective management of medical emergencies:

- As discussed earlier in section II.A.1.b, the investigation of X.X.'s sudden death in July 2007 revealed that two attending staff members failed to provide CPR after finding X.X. unresponsive in his bed because they simply "did not think to do it." Reportedly, when a staff member found X.X. unresponsive, laying face down in his bed, she unsuccessfully attempted to wake him. She then allegedly yelled for another staff member to call an emergency code. Reportedly, instead of immediately calling the code, the staff member ran to the room and attempted to wake X.X. without success. The staff member then

allegedly reported the incident to the facility operator, who in turn, paged the nurse.

- Despite a documented history of swallowing difficulties, A.S., a 67-year-old resident, died in February 2008 after choking on a food bolus. The Emergency Center Nursing Flowsheet from St. James Hospital indicated, "did not attempt the Heimlich." The Medical Emergency/CPR Case Review form indicated that it "took over 5 minutes to activate" emergency notification procedure. "No idea," was the documented answer for the form questions, "Was the emergency intervention initiated within 2 minutes of the occurrence?" and "Was the intervention implemented correctly?" Progress notes from the physician responding indicated the Heimlich maneuver was tried, but no details were included. Progress notes from direct support staff were not available for review.

- A.G. died at Howe in January 2008. Staff found her unresponsive on a couch in a common area, already blue/grey in color. Four months before her death, A.G. had fallen to the floor from her bed, but despite the seriousness of her fall, Howe failed to send her to the emergency room until the next day, when she began to develop a change in consciousness and shortness of breath. At that time she was noted to have four fractured ribs and a large pneumothorax,[11] requiring placement of a chest tube. Additionally, A.G. was also noted to have a lost a significant amount of weight in the months prior to her death – more than 10 percent of her body weight in a three-month period – yet there were no documented concerns or plans to address the weight loss.

3. <u>Nursing Assessments</u>

We find the nursing assessments at Howe generally to be incomplete and fragmented. It also appears that in many cases, nurses are not conducting assessments at all, but instead are simply duplicating the results of prior assessments. Of particular concern are assessments of residents with acute illnesses and injuries. For example, in January 2007, Howe staff measured Z.Z.'s blood pressure to be 145/86 while in restraints. Z.Z. remained in restraints for two hours, but the attending nurse did not flag this high blood pressure reading, and did not conduct an appropriate physical assessment. Below, we detail several areas

---

[11] Pneumothorax is a collection of air or gas in the pleural cavity, which can cause the lungs to collapse.

in which the nursing assessments at Howe substantially depart from generally accepted professional standards.

Nursing assessments at Howe are not adequately integrated into the residents' individualized support plans ("ISPs"). Part of the ISP should be an individual health care plan ("IHCP"). The IHCP should be periodically updated throughout the year to reflect changes in the resident's health status and goals. The goals and outcomes of the IHCPs at Howe, however, are updated only once a year. Of all the IHCPs our expert consultant reviewed, only three were updated prior to the resident's annual interdisciplinary assessment. This means that the individual's treatment team is not provided with the individual's current health status when determining necessary supports and services. Treatment of residents' health care is an ongoing process and such infrequent evaluation of the nursing needs of residents fails to meet acceptable standards of care.

Additionally, the participation by the nurses in the interdisciplinary treatment team meetings that produce the ISPs is inadequate. Information obtained from nursing assessments and nursing diagnoses is not reflected within the ISP process. The nurses' role in the care and desired outcomes of Howe's residents is fragmented at best. In general, nurses are not proactive with regard to the health care outcomes of residents. Preventative care is particularly important for residents at Howe with diminished communication skills who cannot easily identify and convey health issues.

Nursing care plans at Howe are general and non-specific, and often do not include individualized interventions to prevent recurrence of illnesses. We find the recommendations contained in the nursing care plans fail to delineate individual-specific signs and symptoms to be monitored. This is particularly concerning for residents identified at high risk for injury or illness. Moreover, nurses at Howe are not providing consistent monitoring and complete documentation regarding chronic health care issues, such as constipation and aspiration, which are life-threatening conditions for many health-compromised residents at Howe.

Further, pain assessment and individual manifestations of pain are not documented in the nursing care plans. Residents' pain may manifest in behavioral symptoms, such as depression, anxiety, aggression, or decreased socialization. All of these may lead to a decrease in pain tolerance, or unnecessary administration of psychotropic medications that treat the behavioral symptoms of the pain, but do not address the cause of the pain.

The recognition and documentation of individual manifestations of pain is particularly important, given Howe's heavy reliance upon temporary, part-time nurses to provide care. Indeed, our expert consultant asked Howe's Director of

Nursing how a temporary part-time nurse would know whether a particular resident was in pain. The Director replied that the incoming nurse would have to obtain such information from the direct care staff. If the documentation were adequate, then any nurse could rely on residents' charts to better understand their needs and behaviors, and would not need to rely on the assessments of the direct care staff, who are often not medically trained professionals.

Inadequate documentation by Howe nurses is also problematic. When notes are made in the flow sheets and logs, they are often incomplete, failing to fully describe the health event, and hindering adequate follow-up care. For example:

- Menstrual cycle records are often incomplete, particularly in Z.Z.'s case, where no explanation is provided for long gaps in the record.

- Long gaps appear in the sleep records of residents, particularly in the case of G.G.

Inadequate documentation is also present in the nursing progress notes. A nursing progress note should fully describe the condition presented, and each subsequent progress note should address the condition until resolution. The majority of nursing progress notes reviewed by our expert consultant, however, did not contain a description, action taken, or follow-up action, for the conditions presented. Moreover, Howe progress notes are disconnected – failing logically to flow from shift to shift – and result in a lack of appropriate follow-up care to the condition presented. Progress notes also include vague expressions and relative terms with little diagnostic value, such as "good day," "ate well," or "quiet night." Further, dated progress notes are often not in chronological sequence, hindering review even when the progress notes are adequate.

4. Physical Therapy and Nutritional Management

Howe does not provide sufficient physical therapy services. Physical therapy is critical to the residents of Howe in order to maintain their motor skills, joint range of motion, gait training, and posture. Many residents at Howe remain in Individual Positioning Devices ("IDPs"), such as wheelchairs, without a specific medical indication that such confinement is necessary. Confining residents unnecessarily to IPDs greatly increases the risk of osteoporosis, atrophy, scoliosis, skin breakdown, and muscle weakness over time, and needlessly complicates placement in a more integrated setting. Some Howe residents are ambulatory, but nevertheless use IDPs to prevent falls or to facilitate transport. This practice will foster regression of ambulation skills. These deficiencies violate the Constitution.

Due to a high and unmanageable caseload, the physical therapists at Howe do not have time to conduct ongoing training and evaluation of direct care staff to ensure that physical therapy programs are being adequately implemented. Direct care staff is responsible for the majority of the motor skill needs of residents, but are inadequately trained for this responsibility. It appears that Howe provides new direct care staff with minimal training on only transfers and positioning.

Again, due to a high and unmanageable case load, the physical therapists at Howe reactively address the most serious cases, leaving many residents with physical therapy needs untreated. In addition, the caseload is likely causing other issues that we observed, such as:

- Physical therapists do not routinely review positioning plans.
- Evaluations do not routinely include long-term physical therapy goals to optimize or maintain residents' independence. Evaluations also do not routinely include a baseline functioning assessment.
- Physical therapists rarely attend interdisciplinary treatment team meetings, and consequently, have been unable to communicate to other Howe professionals the physical therapy needs of the majority of residents.

Of particular concern regarding physical therapy is Howe's failure to conduct adequate root-cause analysis of resident falls. This failure places Howe residents at risk of injury. Successful fall prevention requires a thorough clinical assessment of residents who fall (or have a history of falls) and their environment. After a fall, clinical staff should evaluate orthostatic blood pressure; extrinsic factors (e.g., wet floor, loose rug); intrinsic factors (e.g., seizure disorder); and medications. A thorough assessment of gait and balance should be included in the evaluation. Further, the appropriateness of mobility devices, such as walkers and wheelchairs, and the need for personal assistance should be reviewed regularly and re-evaluated as necessary. Such steps, which will decrease the risk of future falls, are not currently being taken at Howe.

Another area of concern is Howe's general nutritional management, and its physical and nutritional management of residents with swallowing difficulties. Howe has an Interdisciplinary Nutritional Management Committee that meets at regular intervals to discuss the nutritional management needs of residents and the current meal plan. The outcomes of these committee meetings, however, are not effectively communicated across disciplines. For example, a Howe nutritionist stated that the nutritionists were not routinely informed of changes or additions of medications, particularly antibiotics.

Additionally, individuals at Howe with dysphagia (swallowing disorder), and those at risk of aspiration are not assessed on a routine basis, and the nutritional management team has not developed levels of care to prioritize residents with the most serious and acute needs for services. Similarly, Howe residents diagnosed with Gastro-Esophageal Reflux Disease ("GERD") do not have detailed positioning plans. Howe does not have a comprehensive positioning program, which is critical for proper swallowing, adequate digestion, and nutritional management. Further, there does not appear to be a process at Howe to reassess or modify a positioning program should a swallowing event occur (e.g., choking, gagging, or coughing).

We reviewed meal plans at Howe and found them to be easy to read and understand. Our observation of meals, however, revealed that positioning is not implemented on schedule. Physical and nutritional plans are not adequately individualized (i.e., no choices are provided), and do not address varied settings where swallowing difficulties occur. These concerns in physical and nutritional management place residents at Howe at risk of significant injury.

5. Infection Control

The Howe Infection Control Committee ("Committee") plans for and manages the facility's response to outbreaks of infectious illness, specifically in critical areas regarding the current guidelines for methicillin-resistant Staphylococcus aureus ("MRSA") treatment and management. Our expert consultant reviewed the minutes of the Committee's meetings from 2006 and 2007, as well as the Howe Infection Control Manual. The Committee adequately discusses current infection control issues and anticipates and plans for seasonal patterns of infectious disease. We note, however, that a centralized record showing the updated immunization status of each resident and employee was not available at the time our tour.

6. Pharmacy Services

We have found Howe's pharmacy services to be constitutionally inadequate. Generally accepted professional standards regarding pharmacy services for a facility such as Howe require routine review of medication regimens by pharmacists, and effective communication between the pharmacists and the prescribing clinicians. Howe substantially departs from these standards. Reviews of medication regimens are irregular and infrequent. When the reviews do take place, identified issues are not effectively communicated to the prescribing clinician.

Our expert consultant reviewed the "Medication Quarterly Reviews by Client" for the period of March 1, 2007 through November 30, 2007, and found that all of the reviews were conducted in either June or November. That is to say, there was not a single medication review during the 5-month period between June and

November. Some residents were identified as having even longer gaps between medication reviews, such as A.J. (19 months), C.G. (13 months), C.H. (8 months), and A.K. (7 months). In A.L.'s case, the combination of medications prescribed put A.L. at risk of a fatal rash (Stevens-Johnson Syndrome) and required careful monitoring that, as evidenced by the 13-month gap in review, did not happen. Our expert consultant similarly reviewed the Drug Regimen Review Findings forms from January 1, 2007, through November 30, 2007, and most of the reviews occurred in either February or November. With only a few exceptions, no reviews were conducted during the nine-month period between February and November.

In reviewing the "Medication Quarterly Reviews by Client" and the "Drug Regimen Review Findings," it is apparent that the communication between the pharmacist and the prescribing clinicians is ineffective. Many reviews included comments or requests for clarification by the pharmacist, who identified serious concerns with the choice or dosage of prescribed medication. It is not clear from the reviews, however, what, if any, action was taken by the prescribing clinician in response. For example, in one review a request for clarification was noted because A.M. shares a last name with another resident, and it appears that a medication prescribed to A.M. was actually meant for the other resident. In another example, a request for clarification was made regarding C.I.'s prescription of non-enteric-coated aspirin, which could be dangerous if C.I. has a history of gastrointestinal bleeding, stomach ulcers, reflux, or gastric sensitivity.

In addition, there had been no Pharmacy and Therapeutics Committee meetings at Howe for at least the six months prior to our tour in December 2007. There appears to be a state-level Pharmacy and Therapeutics Committee, but it does not appear Howe is represented on this Committee.

The substantial departure from generally accepted professional standards of care at Howe regarding pharmacy services places the residents at risk for significant medical complications, adverse drug reactions, and potentially even death. Individuals with developmental disabilities are at great risk for adverse drug reactions and side effects from medications. The need for dedicated and frequent oversight of all medication use is imperative for patient safety.

7. Medication Administration

Currently, Howe has no formal system in place to track medication error data adequately, or to analyze such data to identify problems, plan for improvements, implement changes, and evaluate the effect of changes. Moreover, there are no regular forums at Howe in which such data are shared and discussed with the nursing staff. These absences are a substantial departure from generally accepted professional standards.

During our tour, Howe's Director of Nursing stated that medication errors were rare at Howe. We have found, however, that the medication error reporting system at Howe is ineffective, and communication at all levels of the nursing staff is poor. The lack of an effective reporting system and poor communication suggest that medication errors may not be accurately identified and reported.

Additionally, two other medication administration issues at Howe suggest the potential for medication errors. First, nurses at Howe are responsible for administering medication to several housing units, and often to so many residents as to exceed what can safely be managed. Second, because of Howe's low retention rate among nurses, newly hired and temporary nurses are reassigned frequently and are unfamiliar with residents' identities.

8. Dental Care

Dental care at Howe falls substantially below generally accepted professional standards and places residents at an unjustifiable risk of harm. Generally accepted professional standards require that residents receive routine dental care every six months, and that oral x-rays be completed annually. Routine dental care facilitates early detection and treatment of oral disease. Such care is particularly critical for individuals with developmental disabilities because they may be nonverbal or may have difficulty communicating pain or discomfort.

Generally accepted professional standards also require that individuals with disabilities be positioned appropriately when receiving dental care services. Proper positioning is important to ensure residents' safety because they may have a higher risk for aspiration, have skeletal conditions that must be taken into account, or exhibit combative behavior because of their disabilities.

Substantially departing from generally accepted professional standards, 215 of the 332 Howe residents we reviewed were not receiving any routine dental care. For these residents, dental care consisted only of emergency care and/or necessary extractions. These residents received dental care under general anesthesia only. Another 100 residents received comprehensive dental care, also under general anesthesia. Only 17 residents participated in limited dental exams and treatment on site without anesthesia. Even in the small number of instances where the facility did provide routine dental assessments, the assessments tended to be annual instead of every six months. Moreover, x-rays were conducted rarely, only when "absolutely necessary," even where residents' records noted that they had serious dental problems like moderate to severe gingivitis, periodontitis, or bleeding gums. Further, and again contrary to generally accepted professional standards, residents at risk for dysphagia were positioned at a uniform angle for dental work,

despite the recommendations of speech pathologists, who indicated that more individualized positioning was necessary.

Howe's failure to provide routine dental care to the majority of its residents and position them properly when they receive dental services places residents at risk of serious harm. Lack of routine dental care may result in delays in treatment, which may lead to infections, abscesses, need for extractions, and systemic disease, including heart disease and bacterial infections in the blood. Dental pain can also manifest itself in a variety of other types of harm, including behavioral and nutrition problems, choking, and aspiration. Finally, among other complications, improper positioning places residents at risk of aspiration.

9. Nursing Staffing and Training

Shortages of nurses have led Howe to rely heavily upon temporary part-time nurses, and have forced many nurses to work excessive overtime. For example, our expert consultant reviewed the staffing schedules for July and August 2007, and found that 68 shifts were "doubles" – that is, a nurse worked a 16-hour double shift, and 81 shifts during the month of August were staffed by temporary part-time nurses. During this period there were 67 medical incidents or injuries that required transfer from Howe.

Staffing information at Howe is fragmented and logged manually within the separate residences. The scheduling and planning of nurses across residences is conducted by the Director of Nursing, and does not appear to account for the individual needs and levels of care of residents within each of the residences. For example, House 105 is the residence with Howe's most medically fragile residents, yet until just prior to our tour, it was understaffed by nurses.

Howe's system of staffing nurses is inadequate and jeopardizes resident safety and quality of care. Howe lacks a centralized, computer-based staffing information system, and at the time of our tour, was unable to present us with complete information regarding staffing minimums and ratios of nurses to residents. Howe's information regarding staffing is disorganized, and therefore, provides very little meaningful data necessary for appropriate staffing planning and scheduling.

Furthermore, Howe lacks an adequate nursing training program. The training provided at Howe is not uniformly competency-based. Nurses are not routinely evaluated on whether they are capable of competently performing the skills presented in the training and necessary for their duties at Howe.

Howe's nursing staffing is insufficient, and Howe's system of nurse training programs are inadequate. Both of these deficiencies are major contributing factors to the constitutionally inadequate nursing care provided at Howe.

10. Medical Records

Howe's record keeping practices substantially depart from generally accepted professional standards that medical records be organized, accurate, and up to date. Facilities like Howe should maintain all medical records in a uniform organizational format; enter notes legibly; clearly mark sections of the medical chart to delineate the contents within each section; note documentation errors properly; indicate the type of note being entered; indicate date and time; sign notes; file documents properly into the correct patient's chart; and, timely add documents to residents' charts to keep records current. Following these protocols is critical because medical records are vital in capturing, sharing, and storing necessary information to provide timely, appropriate, and potentially live-saving medical care.

At Howe, residents' medical records are poorly organized and extremely difficult to follow. Instead of maintaining one master chart for each resident in one easily accessible place, Howe keeps two charts for each resident in two separate locations; a resident's medical chart is located in the healthcare home, while the rest of the chart is located in the home in which the resident lives. In addition, different functional areas use separate sections of residents' charts. These practices create a disjointed record that makes it challenging to get an accurate and complete picture of the residents' condition at any particular time.

Additionally, Howe fails to audit its medical records to ensure that they are organized, accurate, and current. Our review indicated that records contain filing errors, including instances in which documents for one resident are erroneously filed in another resident's chart. Progress notes and consultations are frequently out of order or misfiled, some notes reference notes that are missing from the file, and other notes are illegible or inconsistently signed. Further, Medication Administration Records ("MARs") and Treatment/Procedure forms from previous months that should have been included in residents' medical charts had not yet been filed as of the time of our tour.

Moreover, although Howe maintains 24-hour nursing logs that contain valuable information about residents, these logs are shredded after three months. Unfortunately, prior to the destruction of these records, Howe makes no effort to transcribe relevant information into individual files; at most, staff verbally report the information in the nursing logs, making it likely that this information will be lost permanently.

Finally, the lists we were provided that named residents who had identified health risks and conditions (e.g., choking, pica) did not consistently correlate with risks identified in these residents' medical records. For example, residents whose medical records clearly identified and addressed specific risks for a particular condition did not appear on the list of individuals at risk for that condition. In other instances, residents were on the at-risk lists provided to us, but their medical charts did not reflect that the identified risk had been noted or addressed.

Howe's substantial departure from generally accepted professional standards in medical record keeping places its residents at risk of harm. Inconsistent organization, documentation, and filing in medical records can prevent health care providers from being able to find needed information about a resident. This can lead to potentially fatal errors, duplication of care, and inaccurate diagnosis and treatment. For example, if a resident's disjointed and inaccurate record prevents a physician from becoming aware of a prior serious problem, like a bowel impaction, the physician may not be able to recognize the early signs of discomfort upon a recurrence of the problem. This could result not only in unnecessary pain and discomfort for the resident, but could also progress to severe impaction - an emergency that may result in bowel rupture and death.

11. Quality Assurance

Howe's "reactive" approach to medical care is further evidenced by the facility's shortcomings in the area of quality assurance. Effective quality assurance management is vital to identifying deficiencies that can be corrected through changes in policies, procedures, or other corrective actions. Ineffective quality assurance management leads to preventable negative outcomes, which result in residents suffering unnecessarily.

Central to effective quality assurance management in a facility such as Howe is continuous communication between the members of the health care team. The communication at Howe between the various members of the medical staff is inadequate. Generally accepted professional standards require that communication between members of the health care team occurs, not only through residents' medical charting and progress reporting as discussed in several sections above, but it must also occur through quality assurance committees and through clear policies and procedures.

Howe does not have quality assurance committees in place. For example, there is no quality assurance and improvement committee, utilization review committee, or peer review committee. The absence of such committees prevents the development of proven quality assurance measures such as: (1) systematic

monitoring of the quality of care being provided; (2) identification of the underutilization and overutilization of health care interventions being provided; (3) assurance of timely access to needed care when indicated; and (4) prompt identification of systemic issues or trends that require intervention.

Further, Howe's policies and procedures are not regularly reviewed and updated to reflect current, generally accepted practices. Clinical policies and procedures at Howe do not appear to have been reviewed for many years.

D. PSYCHIATRIC CARE

Constitutional and other federal standards require that state-operated facilities like Howe provide adequate mental health care for their residents with mental illness. Below, we discuss the psychiatric care at Howe, and conclude that the facility is violating those standards. In particular, for residents with psychiatric care needs, Howe substantially departs from generally accepted professional standards in: (1) conducting adequate initial comprehensive psychiatric assessments, as well as follow-up assessments; (2) providing adequate psychiatric involvement and coordinated care with other treating professionals; (3) regularly monitoring for movement disorders in residents who are on antipsychotic medications; and, (4) providing psychotherapy services.

1. Psychiatric Assessments

Generally accepted professional standards require facilities like Howe to provide residents needing psychiatric care with an adequate initial comprehensive psychiatric assessment. Among other things, this assessment should include presenting concerns; current, past, family, social, and medical histories; current medications; allergies; a mental status exam; and a diagnosis. This assessment also should provide recommendations and a treatment plan, and should indicate when the resident will be seen for follow-up. Follow-up assessments should take place based upon clinical need, typically between one and three months after the assessment. Adequate comprehensive assessments are important for improving accuracy in diagnoses, preventing the prescription of inappropriate or unsafe medications, and assisting the psychiatrist in developing an effective treatment plan. Routine follow-up appointments allow psychiatrists to assess the effectiveness of treatment and address concerns quickly and effectively.

In substantially departing from these generally accepted professional standards, Howe fails to conduct adequate psychiatric assessments of residents. The assessments our expert consultant reviewed consistently failed to contain all the elements necessary to indicate that a comprehensive assessment had been completed. Specifically, at Howe, assessments do not contain necessary details

regarding medical history, family history, and relevant social and environmental issues that could be contributing to a resident's present illness. Assessments routinely fail to document the need for follow-up care and when it should occur. They also fail to indicate whether previous psychiatric notes were reviewed or state who was interviewed as part of the assessment, often even where a resident is nonverbal. Additionally, progress notes in charts consistently indicated "none" next to "medical concerns relevant to this psychiatric consultation," which is unusual as residents undergoing a psychiatric consultation will often have medical conditions relevant to the psychiatric diagnosis and/or treatment options.

Our expert consultant also observed that the information contained in assessments did not provide a clinical basis for the resulting diagnosis, medication, and treatment recommendations. For example, A.N. was diagnosed with pica during an annual psychiatric assessment, yet the psychiatric note contained no documentation supporting how the diagnosis was made or how it would be addressed. Another resident, A.O. had diagnoses of psychotic disorder not otherwise specified ("NOS") and mood disorder NOS, but these diagnoses were inconsistent with other diagnoses listed in A.O.'s records. Moreover, none of the psychiatric diagnoses supported the need for the medication the psychiatrist recommended for A.O. in the progress notes.

Howe's failure to provide adequate, comprehensive psychiatric assessments places residents at risk of serious harm. The lack of important information regarding family, medical, social, and environmental history may result in inaccurate diagnoses and the worsening of symptoms because of inappropriate, ineffective, or delayed treatment. Moreover, the lack of routine follow up leads to crisis-oriented care in which the psychiatrist is consulted only where behavioral concerns escalate.

2. Coordination of Care and Psychiatric Involvement

Generally accepted professional standards require coordination of residents' care between psychiatrists and other treating professionals, including primary care providers, psychologists, and therapists. Such coordination decreases the risk that multiple clinicians may not be aware of what their counterparts may be prescribing or treating. For example, some psychiatric medications may not be appropriate for individuals who have certain health conditions. Moreover, because individuals with developmental disabilities may have difficulty communicating directly with care givers, it is particularly important for treating professionals to collect information about individuals from one another. For psychiatrists in particular, generally accepted professional standards dictate that they should communicate their findings and recommendations with clinical teams and should be readily available for consultation and prompt follow up regarding, for example, medication changes.

Finally, primary treating physicians should respond to psychiatric recommendations promptly.

Our expert consultant's review concluded that Howe fails to provide coordinated care to its residents with psychiatric needs, fails to provide adequate psychiatric involvement, and fails to respond promptly to psychiatric recommendations. These failures express a substantial departure from generally accepted professional standards. Psychiatric assessments often do not include any indication that the psychiatrist reviewed the resident's medical chart or consulted with other individuals involved in the resident's care. For example, the records of resident, E.E., had no indication of such review even though E.E. has "no intelligible speech;" the records of A.P. had no such review even though this resident was "talking nonsense to himself;" and the records of A.Q. had no such review even though this resident is "nonverbal."

Additionally, even where a resident, C.H., had a history of four psychiatric hospitalizations, his records contained no indication that psychiatry professionals at Howe had discussed his case with psychology or other treatment team staff, or that progress in obtaining desired outcomes was addressed. Similarly, the initial psychiatric assessment of A.R., a resident who had recently been admitted to the hospital, contained no indication that her hospital records had been reviewed.

In addition to failing to coordinate care, Howe fails to provide adequate psychiatric involvement for residents who have psychiatric needs. Even where residents exhibit extremely challenging behaviors, the frequency of psychiatric involvement at Howe is minimal. Part of Howe's failure in this regard appears to be a result of staffing difficulties. Since Howe's psychiatrist left approximately one and a half years prior to our tour, the facility has been providing only rotating psychiatric coverage.

Examples of Howe's failure to provide adequate psychiatric involvement to residents include:

- In 2003, C.J. was prescribed Risperdal[12] at a dosage that exceeds the FDA-approved dosage. This resident also was noted to have constipation, seizures, hyperlipidemia, and cardiac concerns – all of these are conditions to which Risperdal is known to contribute. A psychiatric note dated April 27, 2007 indicated that C.J. did not tolerate lower dosages of the medication. As of the time of our visit –

---

[12] Risperdal is a medication used to treat conditions such as schizophrenia and bipolar disorder.

more than seven months after this note was written – the chart contained no indication of additional psychiatric involvement for this resident, despite his clear need for much closer monitoring.

- C.H. was referred for a psychiatric evaluation. A note in his record indicated that the psychiatrist tried to see him on September 22, 2007, but was unable to do so because the resident was on a home visit. The psychiatrist noted that he spoke with staff and that he planned to see the resident later. As of our tour, approximately two and a half months later, C.H.'s record contained no indication that he received the psychiatric evaluation for which he had been referred. This is particularly concerning given that, as noted above, this same resident had a long history of psychiatric hospitalizations.

Additionally, we found an instance where the psychiatrist made numerous recommendations regarding changes to a resident's medications without ever examining the resident and without taking into account medication changes that may have been occurring while that resident was admitted to the hospital. Specifically, while resident A.S. was in the hospital for mania, the psychiatrist wrote in A.S.'s record that the psychiatrist's report was based on "chart review and discussion with interdisciplinary teams. I have not examined [A.S.]. The following nonetheless is based on thorough review and current scientific thinking." The psychiatrist proceeded to make multiple recommendations to adjust medications, without any regard as to what changes were being made at the hospital, and without any mention of a plan for a consultation once the resident returned from the hospital. The only other psychiatric note in the record was dated more than three and a half years prior.

We also found that Howe's primary treating physicians fail to respond promptly to psychiatric recommendations, thereby delaying care for residents, sometimes for months or longer, and placing them at risk of serious harm. For example, on March 16, 2007, the psychiatrist recommended that F.F. be started on Depakote.[13] The order for this medication, however, was not written for nearly three months. Moreover, approximately two and a half months after the order was finally written, the psychiatrist recommended that the dosage be increased, the resident's blood level re-checked, and that the resident be started on Risperdal. It appears that none of this was done at the time of the recommendation. Instead, approximately two and a half months after the second recommendation, Depakote was finally increased and an order was written to check the resident's blood levels

---

[13] Depakote is a medication that may be used to treat conditions such as seizure disorder and bipolar disorder.

in another two weeks. The only other psychiatric note in the record was from three years prior.

In short, Howe's failure to provide coordinated care and sufficient psychiatric involvement, as well as the failure of treating physicians to timely implement psychiatric recommendations, substantially departs from generally accepted professional standards and places residents at risk of serious harm. As noted above, the lack of routine follow-up and continuity leads to crisis-oriented care where the psychiatrist is consulted only when behaviors have escalated. Delays in responding to recommendations contribute to continued symptoms and potentially worsening of the behavioral health condition, which can lead to unnecessary hospitalization, increased injury to self or others, and increased use of physical or chemical restraints. These deficiencies may undercut the other care and treatment provided at Howe, making it more difficult for the individual to move to a more integrated setting.

3. Monitoring of Residents on Antipsychotic Medications for Movement Disorders

Contrary to generally accepted professional standards, Howe routinely fails to adequately monitor residents who are on antipsychotic medications for movement disorders. Generally accepted professional standards require facilities like Howe to provide such monitoring, using standard assessment tools, every six months. Monitoring for movement disorders is critical because antipsychotic medications may cause tardive dyskinesia.[14] Howe's failure to regularly assess residents on such medications for these disorders places residents at risk of serious harm for severe, chronic, and unremitting movement disorders.

4. Psychotherapy Services

The need for psychotherapy services is not being identified in many residents, and when it is identified, psychotherapy services are almost never provided. Group psychotherapy is non-existent. Unfortunately, while it is clear that psychotherapy services are lacking, our expert consultant could not discern exactly what mental health services are being provided at Howe. For example, we received conflicting information as to whether services are provided on-site or off-site, and as to how many residents are receiving services.

---

[14] 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.

E. BEHAVIORAL TREATMENT AND HABILITATION

Howe'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. A fundamental purpose of this training is to enable 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 require that appropriate psychological interventions, such as behavioral treatment and habilitation plans, be used to address significant behavior problems and significant learning deficiencies. Howe fails to provide such psychological interventions to meet the needs of its residents. As described in more detail below, Howe's deficiencies in this regard substantially hinder treatment of residents' problem behaviors, exposing residents to an increased risk of abuse, and compromising residents' opportunities for placement in a more integrated setting. Specifically, Howe: (1) provides residents with ineffective behavioral treatment; (2) exposes residents to undue restraints; and, (3) provides inadequate habilitation treatment and communication therapy.

1. Behavioral Treatment

Behavioral treatment services at Howe substantially depart from generally accepted professional standards of care for individuals with developmental disabilities. As a result, residents are suffering harm because of untreated self-injurious behavior and untreated peer aggression. Further, residents are failing in day treatment services and are being deprived access to community placement because of inadequately treated challenging behaviors. Below, we discuss two areas of behavioral treatment: (a) functional behavioral assessments and treatment planning; and (b) implementation and evaluation.

a. Functional Behavioral Assessments and Treatment Planning

Functional behavioral assessments at Howe are seriously deficient. Generally accepted professional standards dictate that there be an adequate and current functional behavioral assessment in all cases prior to the initiation of behavioral treatment. Functional behavioral assessment is a professional assessment technique that identifies the particular positive or negative factors that prompt or maintain a challenging behavior for a given individual. By understanding the causes or "functions" of challenging behaviors, professionals can attempt to reduce or eliminate those factors and thus reduce or eliminate the challenging behaviors.

Without an accurate assessment of the functions of behaviors targeted for change, those behaviors will persist and become exacerbated, which can result in danger both to the resident and to those around the resident, and can needlessly complicate opportunity for placement in a more integrated setting. It is critical that the function served by the target behavior is defined accurately when choosing a replacement behavior for that target. Inaccurate functional behavioral assessments lead to a choice of replacement behaviors that is unlikely to have any impact on the occurrence of the target behaviors. Howe, however, relies too heavily on a single written screening tool, leaving room for inaccuracy in defining the function of the target behavior. Extensive observational analysis of the behavior problem is needed to verify functional behavioral assessments. Only a proper functional behavior assessment can lead to appropriate treatment options and follow-up services and supports, and Howe, consequently, is failing to make use of critical information about residents.

In fact, replacement behaviors are entirely missing in some behavior plans and are grossly inappropriate in others. For example, several residents have a program simply to teach "waiting." One of these residents, A.O., has a program in which staff are instructed to approach him, ask him if there is anything that he wants or needs, and then inform him that it will be brought to him, but that he must wait for a set period of time. "Waiting" as a replacement behavior is not operationally defined and, in any event, is not a replacement behavior; it does not serve the same functions as a behavior that promptly produces demanded items. Moreover, we have a serious concern about the appropriateness of simply teaching a developmentally disabled resident to wait, as it perpetuates the attitude that individuals with disabilities should be passive recipients of whatever their environment is able to offer them. A "person-centered" approach[15] to treatment planning would suggest, by contrast, teaching individuals to ask appropriately for what they want, to occupy themselves safely and appropriately if their request cannot be met immediately, and to accept some alternative if the request cannot be met at all. Even if "waiting" was considered an appropriate replacement behavior, the intervention used for A.O. – deliberately asking A.O. if he wants or needs something and then telling him he has to wait a certain period of time – is far more likely to induce challenging behaviors than to produce any positive effect.

Similarly, we have observed "compliance" as a replacement behavior, which we find to be vague and subject to abuse. For example, the objective set for A.T. – to "comply 100% for three weeks" – is an unworkable goal. Complicating the issue is the fact that A.T.'s individualized support plan ("ISP") states that

---

[15] "Person-centered" treatment planning is discussed in further detail in Section II.E.1.

"noncompliance" is his means of letting staff know that he is not satisfied with his environment. Given that noncompliance has this identified function, mere reinforcement of compliance is unlikely to have any effect and, indeed, A.T.'s data demonstrate that it has not.

Inappropriate or ineffective replacement behaviors are not recognized as such at Howe, and are therefore not reevaluated, even when it is obvious that they are not succeeding. For instance, after a period of months in which A.B. displayed marked dangerous self-injurious behavior and required mechanical restraints, the replacement behavior devised was to teach A.B. to "sign 'hi' independently." The choice of this behavior was completely inappropriate given the nature and extent of her dangerous behavior, and there is little reason to think that signing "hi" would have an effect on her self-injurious behaviors. In fact, the replacement behavior program had been in place for 18 months at the time of our tour, and the current success rate for the behavior was 5 percent. The success rate was 32 percent when the program started. These low and decreasing success rates obviously indicate that the training program was not working. Notably, the target behavior – dangerous self-injurious behavior – had actually increased.

In general, the goals set for behavioral treatment of Howe residents are far too simplistic to adequately respond to the complexity of the residents' issues. Thus, residents' fundamental needs are not being addressed. For example:

- M.M. engages in the following target behaviors: physical aggression, verbal aggression, property destruction, inappropriate sexual and self-injurious behavior, teasing/provoking, and weapons possession. To address his issues, the procedure adopted is to ask him two questions every evening about the rules for getting along with others and what to do if someone does something he does not like. Establishing the behavior of correctly answering these questions is unlikely to have any significant impact on his dangerous and disturbing target behaviors.

- For A.U., the intervention to establish and maintain "anger management," is for staff, twice a day, to prompt A.U. to count to 10 and then inform him that the counting will help him relax. These interventions are unlikely to teach A.U. to manage his anger, particularly because the prompts are not given when A.U. is angry or likely to become angry, but rather are given on a set schedule.

The inadequate behavioral treatment approaches to self-injurious behavior and pica are particularly troubling at Howe. The primary approach to managing these self-injurious behaviors is to block or redirect the behaviors, rather than to establish an alternative behavior. For pica, the treatment appears to be primarily

environmental, removing or blocking access to things that might be ingested. As a safety plan, maintaining an environment free of suspected pica items is appropriate, although it is extremely difficult to implement comprehensively. That approach, however, is inherently restrictive as a behavioral plan, and it is a barrier to community placement where such environmental modifications cannot be readily provided. If behavior plans are not developed whereby environmental modifications are gradually removed as pica is eliminated, residents will be destined to live in artificially restrictive environments forever.

b. Implementation and Evaluation

Generally accepted professional standards require that facilities like Howe monitor residents who have behavior plans to assess the residents' progress and the program's efficacy. Without accurate monitoring and evaluation, residents are in danger of being subjected to inadequate and unnecessarily restrictive treatment and settings, as well as avoidable injuries due to untreated behaviors.

At Howe, the monitoring and evaluation of behavior plans substantially depart from generally accepted professional standards. The plans are unduly lengthy, routinely employ complicated medical terminology not readily understood by staff, and are not subject to peer review for quality improvement. For example, C.K.'s behavior drill is seven pages long and contains 84 items that staff are supposed to learn.

The Behavior Intervention Committee at Howe, which is supposed to provide oversight of behavior plans, does not accomplish its function. In particular, it does not adequately address the effectiveness of behavioral interventions when approving psychotropic medications or restraint procedures. In many cases dealing with restraints, it does not even discuss the behavior interventions in place to address the behaviors that led to the use of restraints. Minutes from the January 9, 2007, committee meeting illustrate this point:

- Meeting minutes indicate that an antipsychotic medication was to be initiated with C.G. There is no indication, however, of what sign or symptom the medication is intended to target, or any indication of discussion regarding what behavioral interventions were in effect to address that sign or symptom.

- Meeting minutes indicate that an antipsychotic medication and the use of restraints were approved for C.H. There is no mention, however, of any behavioral interventions to address the behaviors that led to the need for restraints or medication.

- Meeting minutes indicate that a medication, mobility restriction, personal property restriction, person and room search, enhanced supervision, and the use of 5-point restraints, were approved for A.A. There is no mention, however, of any behavioral interventions to address the behaviors that led to any of the restrictive interventions.

Moreover, staff training on behavior plans is not competency-based at Howe. Staff training on behavior plans is currently documented by means of a sign-in sheet indicating who was present for the training. Behavior drills that are prepared to allow trainers to document trainees' knowledge of each aspect of the behavior plan are in some cases scored 100 percent correct, although none of the individual items are scored as correct or incorrect. Moreover, the residents' actual behavior drills do not appear to be occurring, as indicated by the relevant line on the behavior plan form, "Number of Behavior Drills (frequency over past six months)," being routinely left blank.

The data collected on behavioral treatment at Howe are unreliable. We noted both missing data sheets and significant mismatches between the recorded data and staff narratives about a resident's behaviors for the same period. For example, while data collected on A.B. showed only a single instance of self-injurious behavior for October 2007, notes from a Special Interdisciplinary Team Meeting stated that A.B. had "increased self-injurious behavior to the point of bleeding, restraints often needed." The Qualitative Monthly Review Summary for October also noted that A.B. "has had many injuries as a result of her [self-abusive] behavior."

Members of the Behavior Intervention Committee acknowledge that behavior data are not reliable. Even dangerous behaviors are not being adequately tracked. For example, the data for A.V.'s pica behavior indicate "zero" instances for November 2006 through February 2007. Yet an x-ray taken during that period showed a metal spring in her digestive tract.

Howe's data collection and analysis regarding "progress toward behavior goals" are not meaningful. There is no reflection of movement toward independence, improved quality of life, or community placement. Data regarding the success of training programs are missing or ignored when decisions are made about continuing the programs. Seriously dangerous behaviors continue or increase without a judgment regarding the need to revise the behavioral intervention plan. Monthly reviews, for example, compare only the current month with the previous month, without interpretation, analysis of data, or any attempt to draw conclusions or make recommendations. There is no consideration of long-term trends. Training on the same replacement behavior persists despite lack of progress over long periods, such as in A.T.'s case, where his baseline success rates for two replacement

behaviors were each 10 percent, and changed very little over four years. Despite these clear failures, Howe maintained A.T.'s program.

In cases in which it is recognized that a resident is not making progress or is experiencing significant deterioration, Howe tends to respond with additional restrictions, as opposed to responding with increased intensity of training, a change in positive intervention, or a new perspective on the problem. For example:

- A.W. has monthly reviews that show 0-3 percent independence for the pica exchange program. The monthly conclusion has always been to "continue program as written." A psychologist's note states that A.W. is making little progress with the pica exchange program, but recommends no revisions.

- A.B. (also discussed earlier in Section D.1.a. of this letter) required multiple meetings because of her dangerous self-injurious behavior, but not a single meeting resulted in a recommendation to revise the behavior plan, which was to sign "hi" independently. Additional restraints were ultimately authorized.

- M.M. had six holding restraints, six mechanical restraints, and one transport restraint in the six months preceding our tour. The behavior plan, however, had remained unchanged for the previous 22 months, although it clearly was not effective in establishing a replacement for the target behaviors.

2. <u>Habilitation</u>

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. Habilitation at Howe substantially departs from the minimally adequate training required by the Constitution, in light of residents' liberty interests. Residents are being harmed because, due to inadequate habilitation assessments and active intervention, they are not able to build skills for success in a more integrated environment. While residents should be learning skills and supports that they will need to pursue their personal goals and improve their quality of life, they are instead being trained in skills that have no real-world application.

At Howe, habilitation assessment results are not being used to select goals. For example, C.L.'s chart states that he "has all grooming, dining, dressing, toileting and domestic skills," but he had active programs for showering and tooth-

brushing. Moreover, the skills to be mastered are not chosen on the basis of movement toward independence. For instance, A.X.'s vocational training program was to sit in a chair for 30 minutes. The purpose of this program is unclear and no supporting assessment data is provided.

In some cases, the training programs do not provide sufficient active treatment. On A.Y.'s individualized support plan, only one program is functional and appropriate ("maintain a shared greeting"). Two other programs teach nonfunctional skills ("matching basic objects" and "responding appropriately to simple questions") that do not foster independence, promote community placement, or improve quality of life.

Vocational services at Howe are limited. Consequently, residents are deprived of opportunities to experience more rewarding vocational activities in more integrated settings. Current generally accepted professional standards increasingly require that individuals receive habilitation services in community settings where the training skills are called into use. For example, a resident would learn money management skills by banking at a bank within the community. Staff at Howe report that vocational and day treatment options are limited because residents attend day activities according to which residence they live in rather than by interest, strength, or goal. Moreover, there are few employment opportunities and job coaches.

When a resident goes to a community-based work setting, active support is necessary for success. The Howe residents who do move to community-based work settings, however, do not receive the support they need. We learned of several residents who quickly lost their jobs because of inappropriate behavior. Residents who fail in community-based work settings are not offered appropriate alternative or remedial programming.

Additionally, the data collection on training programs is deficient. During our November 2007 tour, we saw many blank training program data sheets for programs initiated as early as February 2007. Where there were data, the graphs drawn from the data sometimes did not relate to the data on the data summary. Each of the data graphs drawn for A.Z., for example, showed a steady upward trend, although the number of "steps correct" was consistently zero.

Further, habilitation is a safety issue, and an individual's safety is largely dependent upon the meaningful activity present in his or her life. It is commonly understood that stimulating and challenging activities not only enhance one's quality of life through skill acquisition, but also serve as a deterrent to dangerous and destructive behaviors. Skill development programs at Howe are grossly outdated, some by more than 20 years, adding little meaning to individuals' lives.

Additionally, our expert consultant's extensive record review revealed that the majority of residents' skill development programs were identical from person to person, with only the name being inserted for clarity. For example, B.A. was assigned a grooming goal in 1988, with no revisions indicated, which read identically to others' grooming goals. According to the objectives written, B.A. had spent nearly 20 years learning how to use a towel to dry her body.

Repetitive or monotonous activities will not typically prevent individuals from engaging in harmful behaviors. As the examples below illustrate, sending individuals to programming sites without structured, meaningful activity will not prevent dangerous behaviors or serious injuries:

- In September 2007, while at an off-site day programming activity, C.M. ran up to C.N. while C.N. was seated in her wheelchair, and flipped the wheelchair, causing C.N. to fall and be severely injured. Staff documented that in the future, engaging C.M. in an activity may prevent a similar incident from recurring.

- Upon arriving at her workshop site in October 2007, C.O. began striking herself in the head and banging her head on the floor. Efforts to redirect her were unsuccessful and after 50 minutes of self abuse she was transported to the local hospital for head trauma and numerous self-inflicted bite wounds to her arms.

- In September 2007, during sensory stimulation activities, B.C. fell asleep and tumbled from his wheelchair onto the floor. He incurred injuries to his head and knee, including a laceration on his forehead that required Dermabond closure.

Finally, an important component of habilitation, as well as behavioral treatment, is effective communication therapy. When communication skills deteriorate or are not developed, residents are more likely to be unable to convey basic needs and concerns, more likely to engage in maladaptive behaviors as a form of communication, and are more likely to be at risk of bodily injury, unnecessary psychotropic medications, and psychological harm as a result of having no means to express needs and wants. Failure to provide effective communication therapy serves to perpetuate or exacerbate individuals' challenging behaviors, reduces their ability to express their choices and preferences, and complicates their opportunity for community placement. Howe fails to provide its residents with adequate and appropriate communication therapy.

Many Howe residents lack effective means of communication and are not receiving any communication training at all. In addition, alternative and

augmentative communication systems appear to be underutilized and in some cases inappropriately implemented. Documentation in the charts of residents who engage in dangerous behavior often indicates that the team has abandoned efforts to teach communication skills. Some residents have assessments stating a need to improve communication but have no communication training programs.

Moreover, communication assessments do not identify the most important functional communication goals for the resident, and instead result in programs teaching non-functional skills. For example, B.E. has a program that proposes four months of teaching B.E. to "point to the circle." That is a skill with no functional value at all.

Communication programs that do attempt to teach functional communication skills often do not succeed. This is likely because skills are taught in an artificial context. When skills are not taught in their natural context to persons with developmental disabilities, the behavior learned will not be generalized to the natural context because of the individual's disability. For example, F.F.'s program teaches him to sign "eat" by showing him pictures or giving him verbal prompts rather than by teaching him to use the sign in the natural context of eating.

F. INTEGRATED TREATMENT PLANNING

Many of Howe's difficulties in providing adequate supports and services to its residents stem from the facility's failure to provide integrated treatment planning. The purpose of integrated treatment planning is to ensure that the various disciplines within the facility staff receive, communicate, and consider relevant information about an individual resident when providing supports and services to that resident. 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. Below, we discuss two important components of integrated treatment planning: (1) individualized support plans; and (2) interdisciplinary treatment teams. We find that Howe is experiencing significant difficulties in both of these components, resulting in residents being deprived of constitutional and statutory guarantees.

1. Individualized Support Plans

Howe's individualized support plans ("ISPs") do not reflect person-centered planning, which is the generally accepted standard in intervention and integrated treatment planning for individuals with developmental disabilities. Person-centered planning begins with the individual, examines his or her needs and desired life outcomes, and captures all goals and objectives. Person-centered planning is based on preferences and strengths of individuals. The failure to provide a person-centered approach to integrated treatment planning deprives individuals of opportunities to express choice and preference in selecting goals, undermines efforts to address challenging behaviors, compromises the effectiveness of habilitation programs, and inhibits the ability of Howe residents to move to more integrated settings.

ISPs at Howe frequently do not include a resident's personal goals and preferences, which are the hallmark of person-centered planning. Instead, ISPs at Howe often contain statements such as: "[Resident's name] does not have a personal goal for [this area];" or "[Resident's name] also doesn't have desired outcome for this area." Even where a goal is mentioned, the ISP often does not provide the necessary supports or honor preferences or interventions that will achieve the resident's goal. The ISP for B.G, for example, lists as a personal goal, "to live with a family member." The plan, however, does not state the barriers to achieving that goal, and does not provide any programs that might reasonably be expected to allow B.G to take steps toward reaching that goal.

The assessment process used to develop ISPs at Howe fails to identify skills that are relevant to a resident's progress toward his or her goals. The routine inclusion in ISPs of a self-medication and monetary savings goals were admitted by staff to be driven by the perception that those were goals required for CMS re-certification of the facility.

In general, ISPs fail to include consideration of barriers to the goal of community placement. Without an understanding of the barriers preventing a resident from being placed in the community, it is impossible to identify and implement training that could move the resident closer to placement. Many residents have ISPs that fail to identify any barriers to community placement or any training goals that could move residents forward.

ISP meetings or reviews at Howe, which are held only annually, too often take place without the resident involved, or a guardian or advocate present. This is a critical omission in person-centered planning. When Special Interdisciplinary Team Meetings were held to discuss A.B.'s frequent and serious self-injurious behavior resulting in serious injuries, her guardian requested that an advocate

attend on her behalf. Yet three meetings were held without an advocate or guardian, and without A.B. present.

Additionally, our expert consultant found the structure of ISPs at Howe to be exceedingly difficult to follow. Assessment results, goals and objectives, training programs, and data sheets are scattered throughout the document. As a result, it is difficult to consider the sum total of training, skill development, and overall services. This general disorganization contributes to Howe's failure to produce ISPs that reflect individuals' choices, preferences, and needs.

2. Interdisciplinary Treatment Teams

Howe does not use interdisciplinary treatment teams in its integrated treatment planning. As a result, Howe residents are deprived of coordinated treatment, making intervention efforts ineffectual or inefficient. The only scheduled interdisciplinary treatment team meetings at Howe are held annually as part of the annual ISP meetings noted in the section above. Otherwise, there is no process for holding regular interdisciplinary team meetings to review a resident's progress. Generally accepted professional standards require that each individual's interdisciplinary team meet at least four times a year. Although staff reported that there are "Special Interdisciplinary Team Meetings," which are called on an "as needed" basis, having only regularly scheduled interdisciplinary treatment team meetings once a year is contrary to both generally accepted professional standards and Howe's own policy. Howe's Standard Operating Policy and Procedure No. 433 states: "Each month, starting from the date of the ISP, the support plan will be reviewed using a trans-disciplinary process to assess each person's progress toward achieving the personal goals and objectives specified in the Support Plan." (Emphasis added).

The Interdisciplinary Treatment Team Annual Meetings that we observed during our tour consisted largely of reports by individual disciplines with no interdisciplinary discussion, no interdisciplinary problem solving, and no interdisciplinary action planning. Sometimes the meetings failed to include any action planning at all, even to address problems that had been clearly identified. For instance, a Special Interdisciplinary Team Meeting called specifically to address B.H.'s threats of harm to a peer, a staff member, and himself, resulted in no action plan except observation.

Interdisciplinary Treatment Team Annual Meetings do not demonstrate collaboration between disciplines on assessment, program design, or intervention. Moreover, Howe's Qualitative Monthly Review Summaries are not interdisciplinary in nature and as a result, lack critical information about the resident.

Fragmentation in these records reflects the absence of a functional interdisciplinary process in treatment planning and implementation.

When interdisciplinary treatment team meetings are held, essential team members are not present. For example, when a Special Interdisciplinary Treatment Team Meeting was held on November 6, 2007, to address B.I.'s exclusion from a workshop because of her behavior, only residence staff and the speech therapist attended. The team psychologist did not attend, although a behavior plan was reportedly in development. Advocates, even when requested by a resident's parent or guardian, often are not present.

Further, interdisciplinary treatment team meetings at Howe are not responsive to the resident's expressed preferences or concerns. During A.W.'s Annual Interdisciplinary Meeting, for example, A.W. stated a desire to move. That request was completely ignored, and the team members made no attempt to determine what factors were motivating the request. While it appears that Special Interdisciplinary Team Meetings are held when the staff requests them, we found no instance in which an interdisciplinary treatment team meeting was held because of a concern raised by a resident.

III. REMEDIAL MEASURES

To remedy the identified deficiencies and protect the constitutional and statutory rights of Howe residents, the State of Illinois should implement promptly, at a minimum, the remedial measures set forth below. Despite the decision to close Howe, the constitutional violations at the facility will have continuing effects, for which the State must provide relief. The State retains a statutory obligation to transition residents to the most integrated settings appropriate to their needs. Many of these deficiencies could be remedied, in part, by focusing the care and treatment at Howe on moving individuals into the most integrated setting appropriate to the residents' needs:

A. TRANSITION PLANNING

Provide transition, discharge, and community placement services consistent with generally accepted professional standards to all residents at Howe. Even as Howe proceeds to close, the State must guarantee the residents a safe transition to the most integrated setting appropriate to their needs. To this end, the facility should take these steps:

1. Actively pursue the appropriate discharge of individuals residing at Howe 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;

2. 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;

3. 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:

   a. housing and residential services;

   b. transportation;

   c. staffing;

   d. health care and other professional services;

   e. specialty health care services;

   f. therapy services;

   g. psychological, behavioral, and psychiatric services;

   h. communication and mobility supports;

   i. programming, vocational, and employment supports; and

   j. assistance with activities of daily living.

4. 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;

5. Emphasize the placement of residents into smaller community homes in its transition planning;

6. Avoid placing residents into nursing homes or other institutional settings whenever possible in its transition planning;

7. 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:

   a. commencing transition planning;

   b. identifying community providers and other protections, supports, and services;

   c. connecting the resident with community providers; and

   d. assisting in transition activities as necessary. The responsible person or entity shall be experienced and capable of performing these functions.

8. 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. Howe 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;

9. Update the transition plans as needed throughout the planning and transition process based on new information and/or developments;

10. 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;

11. 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. Howe should modify the transition plans, as needed, based on these community visits;

12. 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;

13. Ensure that each individual residing at Howe be involved in the team evaluation, decision-making, and planning process to the maximum extent practicable, using whatever communication method he or she prefers;

14. 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;

15. Give each individual residing at Howe the opportunity to express a choice regarding placement. Howe 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 Howe for many years;

16. If any individual residing at Howe opposes placement, Howe should document the steps taken to ensure that any individual objection is an informed one. Howe should set forth and implement individualized strategies to address concerns and objections to placement;

17. Educate individuals residing at Howe about the community and various community living options open to them on a routine basis;

18. Provide each individual with several viable placement alternatives to consider whenever possible. Howe should provide field trips to these viable community sites and facilitate overnight stays at certain of the community residences, where appropriate;

19. 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 Howe. Howe should identify and address the concerns of family members and/or guardians with regard to community placement. Howe should encourage family members and/or guardians

to participate, whenever possible, in individuals' on-site, community home field trips;

20. 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;

21. 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 Howe with more complex needs. To encourage frequent individual contact, individuals leaving Howe 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 Howe 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;

22. 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:

    a. providing heightened and enhanced service coordination to the individual/home;

    b. providing professional consultation, expert assistance, training, or other technical assistance to the individual/home;

c. providing short-term supplemental staffing and/or other assistance at the home as long as the problem exists; and

d. developing and implementing other community residential alternative solutions for the individual.

23. 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

The decision to close Howe does not relieve the State of its obligation to protect resident from harm. Therefore, Howe must provide incident, risk, and quality management services consistent with generally accepted professional standards to all residents. More particularly, Howe should:

1. Ensure that incidents involving injury and unusual incidents are tracked and analyzed.

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

3. Develop and implement an adequate system for identifying residents at high risk of being injured or causing injuries to others, and those residents who instigate incidents or who are aggressive. Develop and implement plans to address the high risk situations.

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

5. Ensure that all abuse and neglect investigations are conducted thoroughly and accord with generally accepted professional standards.

6. Impose appropriate discipline and corrective measures with respect to staff involved in substantiated cases of abuse or neglect including staff who fail to carry out their responsibilities while providing enhanced supervision.

Regarding the use of restraints, Howe must ensure that any device or procedure that restricts, limits, or directs a residents' 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, Howe should take the following steps:

1. Ensure that restrictive interventions or restraints are never used as punishment, in lieu of training programs, or for the convenience of staff, and that the least restrictive restraint techniques necessary are utilized, and that restraint use is minimized.

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

3. Prohibit the use of mechanical restraints as part of behavioral treatment plans and programs, and limit the use of mechanical restraints to true emergency situations in which there is no other means of protecting the resident or others.

C. HEALTH CARE

Provide medical care, nursing, and therapy services consistent with generally accepted professional standards to residents who need such services. Howe must provide adequate health care even as it proceeds toward closure. To this end, Howe should take these steps:

1. Provide each resident with proactive, coordinated, and collaborative health care and therapy planning and treatment based on his or her individualized needs.

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

3. Clarify policies and procedures regarding communication and coordination of care between medical providers and specialists to ensure that findings and recommendations are addressed promptly.

4. Develop and implement an adequate system of documentation to ensure timely, accurate, and thorough recording of all medical and nursing care provided to Howe's residents.

5. Conduct regular audits to assess the quality of all medical documentation, timeliness of filing documents, and the overall organization of the chart.

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

7. Ensure that medical staff is capable of recognizing, assessing, and managing the physical pain of the residents.

8. Develop and implement criteria by which residents with the highest nutritional and physical risks are identified, assessed, and provided the appropriate nutritional and physical therapy and supports.

9. Conduct a comprehensive assessment of all residents using mobility, therapeutic positioning, or other assistive technology supports, to determine appropriateness of the technology support and to set measurable outcome goals.

10. Clarify policies and procedures regarding prompt communication between pharmacy staff and prescribing physicians when medication concerns arise, so that modifications in the medication regimen can be made without unnecessary delay.

11. Ensure that residents have routine dental examinations every six months, with oral x-rays being completed on an annual basis.

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

13. Provide adequate positioning to residents at risk of dysphagia during dental visits.

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

D. PSYCHIATRIC CARE

Provide psychiatric services consistent with generally accepted professional standards to residents who need such services. The State's decision to close Howe

does not alter the obligation of Howe to provide adequate psychiatric care to its residents. To this end, Howe should take these steps:

1. Develop standard psychological and psychiatric assessment and interview protocols for reliably reaching a psychiatric diagnosis, and use these protocols to assess each resident upon admission for possible psychiatric disorders.

2. Undertake a thorough psychiatric evaluation of all residents currently residing at Howe, provide a clinically justifiable current diagnosis for each resident, and remove all diagnoses that cannot be clinically justified.

3. Clarify policies and procedures regarding communication and coordination of care between medical providers and psychiatric care specialists to ensure that findings and recommendations are addressed promptly.

4. Conduct adequate monitoring of individuals on antipsychotic medications for movement disorders.

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

E. BEHAVIORAL TREATMENT AND HABILITATION

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. These services should be developed and received by residents despite the State's to close Howe. To this end, Howe should take the following steps:

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

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

3. Use these protocols to endure that functional behavioral assessments and findings about behaviors are adequately substantiated, current, and complete.

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

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

6. Ensure that outcomes are frequently monitored, and that assessments and treatments are re-evaluated promptly if target behaviors do not improve.

7. Ensure that all residents receive meaningful habilitation daily.

8. Provide a habilitation 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.

F. INTEGRATED TREATMENT PLANNING

Provide supports, services, and planning that are integrated across disciplines, consistent with generally accepted professional standards, to all residents at Howe. To this end, Howe should take these steps even while it moves toward closure:

1. Ensure that ISPs integrate information across disciplines and reflect collaboration between disciplines.

2. Ensure that ISPs demonstrate individualized planning, including the individual's needs, strengths, goals, and preferences.

3. Develop and implement ISPs that include a section on transition and discharge planning, including the barriers to community placement and the facility's plan to address those barriers.

4. Ensure that ISPs are understandable to the individual served or their guardian.

5. Ensure that interdisciplinary treatment team meetings integrate information across disciplines and reflect collaboration between disciplines, and that the integration and collaboration are appropriately documented.

6. 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 treatment team process.

7. 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.

8. Ensure that transition and discharge planning, including barriers to placement, are routinely discussed at interdisciplinary treatment team meetings.

* * *

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

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

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

We are obliged by statute to advise you that, in the unexpected event that we are unable to reach a resolution regarding our concerns, within 49 days after your receipt of this letter, the Attorney General is authorized to initiate a lawsuit pursuant to CRIPA, to correct deficiencies of the kind identified in this letter. See

42 U.S.C. § 1997b(a)(1). We would very much prefer, however, to resolve this matter by working cooperatively with you. Accordingly, we will soon contact State officials to discuss this matter in further detail. If you have any questions regarding this letter, please call Shanetta Y. Cutlar, Chief of the Civil Rights Division's Special Litigation Section, at (202) 514-0195, or Joan Laser, Assistant United States Attorney, at (312) 353-1857.

Sincerely,

Thomas E. Perez
Assistant Attorney General

Joan Laser for

Patrick J. Fitzgerald
United States Attorney
Northern District of Illinois

cc: The Honorable Lisa Madigan
Illinois Attorney General
Attorney General's Office

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

Mary-Lisa Sullivan, Esq.
General Counsel
Illinois Department of Human Services

Lilia Teninty, Director
Illinois Department of Human Services
Division of Developmental Disabilities

Joe Turner, Director
W.A. Howe Developmental Center