U.S. Department of Justice

Civil Rights Division

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

November 9, 2009

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

Re: Investigation of the 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

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[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 <u>years</u>." (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.

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[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.

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[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."

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[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

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[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

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[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

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[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. <u>Medical Emergencies</u>

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.

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[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

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[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

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.
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