To: Governor Patrick J. Quinn
c/o Chief of Staff Jerry Stermer

From: Anne M. Shannon

Re: Howe Developmental Center ("Howe") - **FINAL REPORT**

Date: June 30, 2009

## Project Overview

Howe is home to 265 residents with severe to profound developmental disabilities. You asked me to study multiple aspects pertaining to the potential closure of Howe in Tinley Park. The project comes in the middle of a process begun several years ago. The project timeframe was from May 4, 2009 to June 30, 2009.

Numerous individuals and groups have invested a great deal of interest, energy and thought in coming to a decision that is respectful of families and of every single Howe resident. The pros and cons of closing Howe have been identified. Howe has been decertified twice and the Department of Justice is expected to issue its findings.

I am very grateful to the many individuals who care about Howe and its residents who volunteered their time and expertise in this project, especially these professionals at Howe: Lilia Teninty, Greg Fenton, Joe Turner, RoseAnn Kohrt, and Dave Piotrowski.

## Recommendations

***I want to emphasize that I was asked to make a recommendation solely on Howe, and not any other SODCs.***

***Assuming that a) each Howe resident will be properly transitioned to a suitable place chosen by the resident, their parents/guardian and transition team and b) then monitored on a regular basis, I respectfully recommend that Governor Quinn close Howe.***

***The report also contains specific recommendations for each stakeholder group and general recommendations based on Howe for the statewide system for individuals with developmental disabilities.***

If you agree, then an announcement of closure will:

1. Trigger a mandatory 60-day notification to negotiate a closure agreement with AFSCME.

2. Accelerate transitions of Howe residents to State Operated Developmental Centers (SODCs), community ICF/MRs (Intermediate Care Facilities for Persons with Mental Retardation) or Community Integrated Living Arrangements (CILAs).

## Specific Points

1. As of June 30, Howe had 265 residents. Decertification means that Howe does not accept new residents.

2. The decision on whether or not to close Howe is very emotional and personal.

3. Each stakeholder group was given a chance to voice their opinions in the process.

4. Each stakeholder group agrees that resident health, safety and well-being are the #1 issue.

5. The federal government requires individuals with developmental disabilities to live in the least restrictive setting possible, which is determined by the individual, their parent/guardian and transition team.

6. A thoughtful process exists for transitioning residents to SODCs, community ICF/MR or CILA.

7. Parents/guardians have expressed a transition preference for 262 of 265 Howe residents and every effort will be made to honor preferences.

**Decertification**

The Illinois Department of Public Health (IDPH) is responsible for ensuring compliance with Centers for Medicare and Medicaid Services' federal ICF/MR rules and regulations. Due to lack of compliance with conditions of participation required by the Center for Medicaid and Medicare, the IDPH recommended that Howe be decertified.

In March 2007, Howe was decertified. Members of the Howe Leadership team generally believe that DHS set Howe up for failure

**Consequences of Decertification**

| | |
|---|---|
| 1. State of Illinois | Howe is ineligible for the federal match for each person served at Howe, which is approximately $2.2 million per month (i.e. $73,000 per day). |
| 2. SODC residents | Because of the time involved in recertification efforts and the lack of a federal match, Howe siphons State of Illinois' personnel and financial resources from other SODCs and the community system. |
| 3. Howe residents | Since Howe does not accept new residents, residents who transition to another facility cannot be readmitted to Howe - even if the transition was unsuccessful. This has been a strong incentive for parents/guardians to avoid transitioning out loved ones. |

**Stakeholder Groups**

These stakeholder groups have been identified, in no particular order:

1. Governor Quinn
2. DHS Leadership
3. Legislators (including the Commission on Government Forecasting and Accountability - CGFA)
4. Staff at Howe
5. Advocates
6. Union
7. Parents and Friends of Howe
8. Residents
9. Day Training Providers

**1. Governor Quinn**

Since Governor Quinn is the final decision maker in this highly emotional situation, this report is intended to define the perspectives of all stakeholders. Parents/guardians question how Governor Quinn can make a decision without having visited Howe.

**Recommendation** *I strongly recommend that Governor Quinn visit Howe before making a decision.*

**2. DHS Leadership**

I met with Secretary Carol A. Adams and Assistant Secretary Grace Hou. Both strongly believe that Howe should close and cite these reasons (in their order of importance):

a. Resident Care
   i. The decertification reports cite significant areas of concern.
   ii. The Department of Justice, under the Civil Rights for Institutionalized Persons Act, is expected to issue negative findings regarding care at Howe.

b. Cost
   i. Decertification means no federal match, which means the State of Illinois must pay the shortfall, which means Howe siphons resources from other SODCs and community services.

**Recertification**

Frontline Howe staff members believe that the Howe Director and Leadership Team are responsible for Howe not being recertified. DHS Leadership counters that the State of Illinois has spent significant resources to recertify Howe, including $7 million (source: DHS response to CGFA), 4 FTEs and 7,000 hours of assistance.

a. From October 2006 to March 2007, Howe received 3,284 hours of administrative oversight, technical assistance and training to staff (source: Ira Collins, Director of the Shapiro Developmental Center, a peer facility to Howe).

b. In April 2007, Sharon Parker was appointed interim director. She brought leadership and strong work experience. Her nursing experience is likely the reason Howe was cited for Best Practice in Preventing Infections.

c. In July 2007, DHS hired the Pennhurst Group and H&W Solutions, nationally-recognized experts in the field of developmental disabilities and the operation of ICF/MR facilities. Howe benefited from 4 FTEs as well as 3,800 hours of technical assistance and consultation.

d. The clinical medical director and nursing staff worked with Howe staff on a regular basis. Expanded information is detailed in the DHS report to CGFA questions.

Because recertification has not occurred despite these resources and efforts, DHS Leadership and experts Ira Collins, Sharon Parker, Pennhurst Group, and H&W Solutions believe that recertification is no longer an option.

**Transition**

In 2007, Director Teninty created a Transition Section responsible for working with Howe staff and Service Coordination personnel to assure successful transitions of residents from Howe. The Transition Section has been highly successful and has greatly increased the transitions of residents from Howe from 19 in FY05 and 13 in FY06 to 24 in FY07, 37 in FY08, 45 in FY09 and 10 expected in July 2009.

A transition team meets weekly to discuss how each resident waiting to transition to another site is moving through the process. Meetings are held at Howe and last up to 2 hours. The team gives out assignments to keep the process moving. I believe that this initiative is highly effective.

**Recommendation:** *I strongly recommend that DHS prepare materials for parents/guardians and Advocacy groups that explain the transition process, highlight a family that has successfully transitioned a loved one, and indicate how to connect with other families.*

*The lack of clarity about Howe's future has caused many parents/guardians to delay a transition decision. They don't want to transition their loved one and then have Howe remain open, particularly because decertification means that Howe does not accept residents back after they leave. If Gov. Quinn agrees with my closure recommendation, then I strongly recommend that he announce it as soon as possible to give these parents/guardians an incentive to accelerate the transition process.*

**3. Legislators (including CGFA)**

Thanks to Matt Langer, I met with CGFA members and other legislators, including Senators Maggie Crotty (D) and Christine Radogno (R) and Representatives Al Riley (D), Kathleen Ryg (D), Heather Steans (D), Elaine Nekritz (D), Kevin McCarthy (R). I also met briefly with Representative Patti Bellock (R) and had a lengthy phone conversation with Representative Sara Fiegenholtz (D).

There is bipartisan support both on wanting Howe to close and remain open. All legislators were generous in their time and very knowledgeable on the issues.

Legislators that support the decision to close Howe include: Senators Bill Brady (R), Matt Murphy (R), Christine Radogno (R), Jeff Schoenberg (D), David Syverson (R); Representatives Patricia Bellock (R), Sara Fiegenholtz (D), Kevin McCarthy (R), Richard Myers (R), Elaine Nekritz (D), Kathleen Ryg (D), Heather Steans (D). Also, in April, CGFA voted 9 to 3 to close Howe.

Legislators who have indicated that they want Howe to remain open include: Senators Maggie Crotty (D), Michael Frerichs (D), Donne Trotter (D); Representatives Raymond Poe (R), Al Riley (D). Senator Maggie Crotty and Representative Al Riley represent the district where Howe is located. Both strongly believe Howe should remain open and made reasonable, unbiased arguments. Representative Riley believes that Howe has not gotten a fair shake and states that residents are very important - but staff is also important.

**Recommendation** *Keep CGFA and legislators informed.*

**4. Staff at Howe**

The staff wants Howe to remain open. They are concerned about potential job loss and/or new work location.

- **Staff-resident ratio**

  Howe has 760 staff (698.5 active, 61.5 inactive) caring for 265 residents. Inactive means that the person is on the books. This can be due to a leave of absence or suspension while an investigation is being conducted.

  Individual Support Plans require that 6 residents have 3 to 1 staffing and 9 residents have 2 to 1 staffing. An estimated 40 staff are for shared services. Thus, Howe has 684 staff for the 250 residents not needing extra care (i.e. 2.7 to 1 ratio), which is high compared to other SODCs (1.84 to 1 ratio).

| | Residents | Staff | |
|---|---|---|---|
| -- | -- | 40 | (shared services) |
| Residents not needing extra care | 250 | 684 | |
| Residents needing 2 to 1 care | 9 | 18 | (required) |
| Residents needing 3 to 1 care | 6 | 18 | (required) |
| Total | 265 | 760 | |

- **Missing Medical Charts**
  The medical charts of 11 residents are missing. Management staff is aware of the issue, agree that a policy exists for signing in/out the charts, and that the policy is rarely followed. The missing charts include private information such as medications and medical history.

- **Responsibility for Decertification**
  Some Howe staff believes that decertification was not the fault of staff and that Howe was set up for decertification ("Why did they pick on Howe?").

- **Overtime**
  Overtime for FY2009 was budgeted at $4.15 million but is now projected at $6.63 million. Howe has the highest overtime as a percent of budget of the 9 DD facilities. Overtime is typically at least 1.5x regular pay.

- **Family Medical Leave Act (FMLA)**
  Howe has 140 staff (21%) on family medical leave. Staff is paid while on FMLA, which increases the staff-resident ratio and overtime.

**Recommendation**

***Training.*** *Howe Leadership states that training could be stronger. Staff should receive more "person-centered" training.*

***Staff-resident ratio.*** *It appears that the employee-resident ratio should be lower and based on the individual support plans of the residents. Since Oct. 2006, staff levels have dropped 2% (13.5) while the number of residents has dropped 40% (160). Had the staff-resident ratio stayed at 1.9x, the staff level would be 462 (298 lower) at July 31, 2009.*

| | *Oct. 2006* | *Dec. 2008* | *6/3009* | *7/31/09* |
|---|---|---|---|---|
| *Staff* | *773.5* | *751.5* | *760* | *760* |
| *Residents* | *398* | *300* | *265* | *238* |
| *Staff-Resident ratio* | *1.9x* | *2.5x* | *2.9x* | *3.2x* |

*Since Howe does not accept new residents, I recommend that staff be proportionately reduced as residents transition out. The State of Illinois should look to placing all qualified staff at other facilities.*

*The high staff-resident ratio is a disincentive for residents to transition out, since their families believe residents receive more care at Howe. However, the decertifications indicate that the high staff-resident ratio has not translated into higher care, and I believe that residents can receive the required level of care with a lower staff ratio.*

*If Howe's 265 residents are transitioned to other facilities, there may be opportunities for the other facilities to hire Howe staff.*

***Missing medical charts.*** *I strongly recommend that a review be done immediately to determine how many residents are missing charts. I strongly recommend that chart procedures be followed and enforced.*

***Overtime and FMLA.*** *It appears that overtime and FMLA are much higher than average. One concern with overtime is that staff working too many consecutive hours can potentially lead to fatigue, which can lead to inadequate care. I recommend that a review be done of overtime and FLMA by staff, including which residents were served by overtime hours and why. I recommend that a study be done to determine if staff with high overtime is correlated to incidents of inadequate care. Reducing unnecessary overtime and FMLA would substantially reduce the cost of Howe during the closure process.*

**5. Advocates**

I met with the Executive Director of each of the following Advocacy Groups for at least 2 hours.

IL-ADD wants Howe to remain open. It believes that an SODC is the best placement for loved ones and there is a concern that if Howe closes, then other SODCs will also close.

| | Group | Position | reason |
|---|---|---|---|
| a) | Arc of Illinois | Close | No option |
| b) | Equip for Equality | Close | Very concerned about resident safety and deaths. |
| c) | The Council | Close | Very concerned about resident safety and deaths. |
| d) | Institute on Public Policy | Close | Very concerned about resident safety and deaths. They hold monthly workgroups meetings at Howe to strategize how to make transitions successful when there are behavioral issues. |
| e) | Advocates United | -- | Supports individual family decision |
| f) | IARF | -- | Concern about resident safety, smooth transition, and long-term supports remaining in place. |
| g) | IL-ADD | Remain open | Represents SODC parents |

**Recommendation** *Advocacy groups should be kept informed.*

**6. Union**

AFSCME is a well-regarded union that wants Howe to remain open for one more year to give time for recertification. They believe that Howe management is responsible for decertification. They believe that the staff are dedicated and perform their work well. There is concern over potential job losses for members.

**Recommendation** *DHS individuals knowledgeable about the working conditions and operations at SODCs should attend closing and transition negotiations.*

**7. Parents and Friends of Howe**

Parents/Guardians want Howe to remain open. Betty Turturtillo, President of the Parents and Friends of Howe, requested that I meet with 50 families. I met with families in groups of 10 to 12. There were 4 meetings of at least 2 hours each with a total of 55 family members/guardians. Each family had a chance to share their story and concerns.

It is obvious that emotions are raw. They know about decertification and about the investigation by the Department of Justice. Many were involved in the poorly-handled transition from Dixon and/or Lincoln and their memories of the painful process are quite vivid. Much misinformation is circulating. Many have neither visited community alternatives nor other SODCs.

- **Transfer Trauma**
  Some parents/guardians are concerned about "transfer trauma" (that loved ones will die because of a transfer). From Jan. 1, 2007 to May 20, 2009, 88 residents were transferred from Howe. From Jan. 1, 2007 to May 31, 2009, 8 of those residents died. Since 3 of the 8 deaths were anticipated when the residents were transferred, 5 out of 85 residents (5.9%) potentially died from "transfer trauma." From Jan. 1, 2007 to April 24, 2009, 24 of 1,000 residents died while at Howe (2.4%). Thus, "transfer trauma" potentially caused the death rate to rise from 2.4% to 5.9%. I cannot determine if "transfer trauma" caused these deaths due to lack of information about health at discharge, age, causes of death, etc. as well as the small sample size and limited time period.

  The 5 deaths occurred in the 13th, 15th, 13th, 10th and 8th month after discharge, or in the 12th month on average. While the sample size is small, the range of time periods is narrow.

- **Intermediate Care Facility**
  Some parents/guardians believe that Howe is a permanent residence. By definition, Howe Developmental Center is an Intermediate Care Facility (ICF). This means that Howe's role is to prepare residents for a transition to the least-restrictive environment.

  Approximately half of the residents at Howe are nonverbal, so parents/guardians make the transition decision. If no decision is made, then Howe becomes a permanent residence. Some Parents/Guardians have made Howe a permanent residence by delaying transition (i.e. not choosing transition, not exploring other living options). Over half of the residents have been at Howe for over 20 years.

| Years at Howe | Residents | % |
|---|---|---|
| 0-5 | 18 | 7% |
| 5-10 | 74 | 27% |
| 10-15 | 12 | 5% |
| 15-20 | 25 | 9% |
| Over 20 | 136 | 51% |
| Total | 265 | 100% |

**Recommendation** *Some family members have not had the opportunity to be trained in their roles, responsibilities, and rights as well as resident rights. This may be due to the age of the residents and the lack of options at the time of their placement. They may not understand the impact of the Annual Habilitation Meeting and Individual Support Plan, which is a legal document. I strongly recommend creating materials on Transition, Annual Habilitation Meeting, Enhancements and Options for Placement as well as End of Life Decisions.*

*If parents do not have resources needed for travel, then a voucher program should be reviewed. If parents need resources to visit other providers, then there should be a creative way of handling the situation.*

***"Transition Trauma".*** *I strongly recommend doing a study to compare death rates of Howe residents with residents who transitioned from Howe*

*to determine if "transfer trauma" exists. The study could include other SODCs. The results should be shared with parents/guardians.*

*I recommend that residents who transition from Howe and other SODCs be closely monitored during the first 18 months after the transfer occurs. I recommend that a monitoring tool be developed to track each resident's transition. This report should be reviewed each year at the resident's annual plan and become part of the resident's permanent record.*

***Intermediate Care Facility.*** *Educate parents/guardians that SODCs such as Howe are transitional facilities that were not originally intended to be permanent residences.*

**8. Residents**

In June, I attended the Resident Council Meeting. 35 residents participated. Everyone had a good time and seemed happy. I believe that Howe is not the least restrictive environment for most of these 35 residents.

**Recommendation** *Approximately half of the residents at Howe are nonverbal, which makes the role of parents/guardians incredibly important. Residents are not making transition decisions; their parents/guardians are. Create links for family involvement so that they understand what is taking place when they sign the annual meeting document.*

**9. Day Training Providers**

St. Coletta's and Cornerstone are two community agencies providing day services to Howe residents. Closing Howe may impact both agencies financially, depending on how many residents will continue to be served in their respective DT programs.

**Recommendation** N/A

**Transition of Howe Residents**
Dave Piotrowski, head of transition efforts at Howe, and I met to determine what would be a realistic transition period if Howe were to be closed. Key factors include the:

1. number of Howe residents to transition (265)
2. time to make a decision (resident, parent/guardian, transition team visits)
3. time to do the transition (paperwork, moving, etc.)
4. time it takes to have trained staff at the receiving residence
5. capacity at other residences

**Transition rates**
Mr. Piotrowski indicated that the projected transition of residents looks like this:

| | Now | expected in July | post-July |
|---|---|---|---|
| Has spoken with 150 private guardians | 148 | 16 | 132 |
| Has spoken with OSG about 33 wards | 33 | 11 | 22 |
| 70 families want community placement | 69 | 0 | 69 |
| Needs to speak with 15 families | 15 | 0 | 15 |
| | 265 | 27 | 238 |

Howe had 24 residents transition out in 2007, 37 in 2008, and 37 in the first 6 months of 2009 (i.e. 6 per month). Based on Howe having 265 residents and the current rate of 6 transitions out per month, the transition process for closure would take 3.7 years. Closing Howe by April 30, 2010 (i.e. 9 months from post-July) requires 27 transitions per month, which is possible but aggressive.

**Transition facilities**
From FY2007 to YTD FY2009, residents transferred from Howe to:

| | FY07 | FY08 | FY09 YTD | Total | % |
|---|---|---|---|---|---|
| CILA (group home) | 22 | 31 | 27 | 115 | 77% |
| ICF/DD | 2 | 5 | 9 | 21 | 14% |
| SNF (skilled nursing facility) | 0 | 0 | 0 | 5 | 3% |
| Family | 0 | 1 | 1 | 8 | 8% |
| Total | 24 | 37 | 37 | 149 | 100% |

However, these residents had parents/guardians who were most willing to transition their loved one. The remaining 265 residents are expected to transition in vastly different percentages. The expected demand (post-July) is as follows: 69 families want community placement, 95 families want the Ludeman facility (which is the closest facility and residents would be in the same day program), and preferences for 74 residents are unknown.

When Lincoln closed, Howe received 109 new residents. Great care must be taken not to overload Ludeman, Shapiro, or any other setting, with Howe residents. Additional staff must be hired and trained prior to transfer of Howe residents. Community placement, Ludeman and Shapiro capacity are being determined. Over the past 5 years, 1,500 additional CILA slots have been created. This will need to continue to keep up with demand created by transitions from SODCs.

| | Known demand |
|---|---|
| Community Placement | 69 |
| SODC | 95 |
| SNF | 0 |
| Family | 0 |
| Unknown | 74 |
| Total | 238 |

**Incident reviews**

Each day, each unit generates a report regarding incidents, allegations, injuries and transfers to hospitals. Unit Directors and Howe Leadership meet daily to review the reports from the previous day. A Unit Injury statistics table is generated each month to reduce injuries.

**Abuse and neglect cases**

Since July 1, 2008, there were 51 cases of abuse and/or neglect. 13 remain open and 3 have been substantiated.

**General observations from Howe applicable to the state system for individuals with developmental disabilities**

**Recommendation** *The Crisis Intervention Project is a group of volunteers from several community agencies that meet monthly at Howe to discuss strategies for dealing with difficult behavior in CILAs. I recommend that this be implemented across the state.*

*I recommend that DHS develops a Master Plan regarding the SODCs.*

*There is a huge gap between what is paid for SODC care and community care. I recommend that DHS adopt a unified and coordinated 'Money Follows the Person' approach to give residents an incentive to transition to the community from a nursing home or institution.*

*I recommend that DHS consider having SODC facilities give more specialized care towards certain populations (including the aging) than generalized care.*

*I recommend that DHS formalize the transition process used at Howe throughout the SODC system.*

*No abuse and/or neglect should be tolerated. I strongly recommend that any staff at fault for a substantiated case of abuse and/or neglect face appropriate consequences.*

**Information Sources**
The method for obtaining relevant information has been: meetings, interviews in person/by phone, site visits, and review of reports pertaining to Howe.

**Meetings, Interviews, Site Visits**
I met with all of the aforementioned stakeholder groups, except for the Day Training Providers. At the request of various stakeholders, I conducted interviews with past and present consultants (Ira Collins, Louise Nash, and Dr. Rod Curtis). I made numerous visits to Howe and had dinner at two homes with residents.

**Reports**

- *Report*, the Taxpayer Action Board, Jun. 9, 2009.
- *An Outline for the Future of the DD Service Delivery System in Illinois – draft*.
- *Responses*, Divisions of Developmental Disabilities and Mental Health, Illinois Department of Human Services to Commission on Government Forecasting and Accountability (C GFA), Jan. 9, 2009.
- *CRIPA Ruling to the Governor of Texas*, U.S. Department of Justice, Civil Rights Division, Dec. 1, 2008
- *Impact of the Closure of Howe and Tinley Park Facilities Report to the Illinois Department of Human Services*, Regional Economics Applications Laboratory Institute of Government and Public Affairs at the University of Illinois-Urbana, Nov. 2008.
- *Plan to Close the Howe Developmental Center - Draft*, Division of Developmental Disabilities, Oct. 2008.
- *State Operated Developmental Centers Consulting Services: Final Report Prepared for the Illinois Department of Human Services Division of Developmental Disabilities Final Report*, Pennhurst Group, LLC and H&W Independent Solutions (joint venture), Oct. 7, 2008.
- *CRIPA Ruling to the Governor of Missouri*, U.S. Department of Justice, Civil Rights Division, Aug. 12, 2008
- *Five-Point Action Plan for Beatrice State Developmental Center,* Nebraska Department of Health and Human Services, Mar. 17, 2008.
- *Blueprint for System Redesign in Illinois Executive Summary*, Human Services Research Institute in partnership with the Illinois Council on Developmental Disabilities, Jan. 2008.
- *Gap Analysis: Services and Supports for People with Developmental Disabilities in Illinois*, Human Services Research Institute, Jan. 2008.
- *Notes from the Department of Justice Exit Interview, W.A. Howe Developmental Center*, Dec. 7, 2007.
- *Survey Documents*, Illinois Department of Public Health, Oct. 17, 2006 and Mar. 15, 2007.
- *Family Issues*, Community for All Tool Kit, 2004.

# Summary of Recommendations from Anne M. Shannon

**Summary**

***I want to emphasize that I was asked to make a recommendation solely on Howe, and not any other SODCs.***

***Assuming that a) each Howe resident will be properly transitioned to a suitable place chosen by the resident, their parents/guardian and transition team and b) then monitored on a regular basis, I respectfully recommend that Governor Quinn close Howe.***

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## 1. Governor Quinn

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## 3. Legislators (including CGFA)

*Keep CGFA and legislators informed.*

## 4. Staff at Howe

***Training***

*Howe Leadership states that training could be stronger. Staff should receive more "person-centered" training.*

***Staff-resident ratio***

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***Missing medical charts***
*I strongly recommend that a review be done immediately to determine how many residents are missing charts. I strongly recommend that chart procedures be followed and enforced.*

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## 6. Union

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*I recommend that a monitoring tool be developed to track each resident's transition. This report should be reviewed each year at the resident's annual plan and become part of the resident's permanent record.*

***Intermediate Care Facility***
*Educate parents/guardians that SODCs such as Howe are transitional facilities that, by definition, were never intended to be permanent residences.*

## 8. Residents

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## 9. Day Training Providers

*N/A*

## General Howe observations applicable to the state system for individuals with developmental disabilities

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