ILLINOIS NURSES ASSOCIATION
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December 11, 2008

Commission on Government
Forecasting and Accountability

RE: Howe and Tinley Park Closures

Dear Commission members;

The Illinois Nurses Association wishes to express its concern regarding the handling of the Howe and Tinley Park facilities. The collective mismanagement of these two facilities has orchestrated this situation and is being used as a means to justify the closure and subsequent selling of the property. Our remedy of choice is to begin fixing the problems immediately, to develop a system that provides safe care at Howe & Tinley Park with adequate nursing staff and place a moratorium on any discussion of closure. Funding must be made a priority to meet the needs of the people who reside at Howe and their families throughout this process. If closure is imminent then, we firmly believe that the state must develop a plan for adequate funding to guarantee a sufficient level of acute care mental health services remain available in this area of the state. We also believe that if any gain is realized from these closures that those funds should remain in the Illinois mental health system.

The second part of our concern is in relation to the nurses employed at these facilities. We would be remiss if we did not address our concern for these individuals. We understand there are many issues at Howe, but remedies are available. The registered nurses at Howe are dedicated professionals with expertise in this area; they are on site and could be instrumental in investigating, strategizing and implementing the necessary changes to make Howe and Tinley Park valuable assets in the Illinois mental health system.

The Illinois Nurses Association has worked hand in hand with several agencies to help minimize the impact of the nursing shortage for the public of Illinois. With that in mind, INA emphatically believes that all nursing vacancies at all of the state facilities must be filled expeditiously. Due to the state's failure to meet the staffing needs of those cared for in the state system, we firmly believe Howe and Tinley Park are not the only facilities within the system who are failing to meet the most basic standards of care. The current mandatory overtime crisis for nurses working in state facilities only serves to put the public of Illinois at risk.

Thank you for your time and consideration to this issue.

Respectfully,

Pam Robbins RN, BSN
President, Illinois Nurses Association

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December 17, 2008

Senator Jeffrey Schoenberg
Senator Larry Bomke
Senator Bill Brady
Senator Don Harmon
Senator Dave Syverson
Senator Donne Trotter

Representative Richard Myers
Representative Patricia Bellock
Representative Frank Mautino
Representative Robert Molaro
Representative Elaine Nekritz
Representative Raymond Poe

Commission on Government Forecasting and Accountability
703 Stratton Office Building
Springfield, Illinois 62706

Dear Commissioners:

The employer of the RC-23 local bargaining unit is the highest official in the General Assembly of the State of Illinois, and the entity with whom the Illinois Nurses Association's Government Relations Committee actively works concerning issues of public safety and nursing practice. The status of the Howe and Tinley Park facilities present a unique situation for the multipurpose organization of the INA.

It is quite apparent that the management of these two facilities has failed in its duty to the state of Illinois. The Department of Human Services' solution to fixing the problems by closing the doors and removing the residents reflects a short-sited, bottom-line mentality. The fact that the management of DHS has chosen to focus on closure due to its inability to effectively plan for and attain re-certification is a testament to a profound lack of leadership skills. The loss of certification and matched federal funds at Howe is creating additional loss of taxpayers' dollars. INA proposes the following remedy:

- Provide safe care and adequate nursing staff at Howe and Tinley Park;
- Place a moratorium on facility closings; and,
- Begin correcting the problems immediately.

The imminent danger of inadequate staffing is perpetuated by the current administration of DHS. The DHS administration has imposed a hiring freeze; this action forces current employees to work many hours of overtime, and places an extreme burden on the state budget. Years of research strongly illustrates that fatigued workers are more likely to commit errors, and are often unable to perform critical thinking skills.

The situation at Tinley Park raises other concerns regarding poor management, while the proposed privatization of this facility creates another set of issues. In its proposal to close Tinley Park and replace it with a privately operated facility, the DHS has apparently failed to provide to procure and provide to the following:

- A contractor;

- An agreement; and,
- A plan to retain current state employees.

The specters of mandatory overtime and ever increasing dangers to patient safety, imposed by the hiring freeze, cast long shadows over Tinley Park. Nurses are forced to work past their physical limits on a regular basis, sometimes working double and triple shifts.

INA stands ready to assist in enhancing the safety of, and services to, the residents of Howe and Tinley Park, while improving the working conditions of the employees at both facilities. Thank you for your time and consideration.

On Behalf of the Association,

Laurence Goehl RN
Chair
RC23 Local Unit Board of Directors

**Written Testimony of Linda Bennett**
**Legislative Affairs Specialist for Medicaid and Medicare Issues**
**American Federation of State, County and Municipal Employees (AFSCME)**
**Washington, DC**

**Before the**
**Illinois Commission on Government Forecasting and Accountability**
**on the Proposed Closure of**
**Howe Developmental Center and Tinley Park Mental Health Center**

Because the proposals to close the Howe Developmental Center and Tinley Park Mental Health Center are controversial it may be useful for us all to step back and consider some fundamentals that most of us would agree should underpin a state system to serve individuals with disabilities.

Foremost -- value the individual.

This requires that we recognize that individuals with disabilities are unique and require different levels of supports, services and care. This may seem obvious but it can help us avoid the false "either/or" paradigm that pits public congregate residences, like Howe Developmental Center, against expanding services elsewhere in the community. Both are needed. When we focus on the different needs of individuals as well as their changing needs over time, and as they age – the either/or focus makes no sense and should be discarded. Valuing and planning for the "individualness" of individuals with developmental disabilities or with mental health requires that we build a system that can consistently deliver an array of services for a lifetime of changing needs. To match the diverse and unique needs of individuals with disabilities such a system needs congregate residences, state hospitals and community and home based services.

The proposal to close these two public centers means a loss of vital services and care that some individuals need now and others will need in the future.

Mental health advocates rejected this either/or framework in the fight to close Tinley Park four years ago. State hospitals support the work of community mental health clinics and private hospitals by caring for individuals when they are more volatile or require longer lengths of stay. The community mental health clinics ensure that individuals, after in-patient treatment, have stabilizing connections to community resources.

The either/or framework is equally false in the context of public-funded developmental centers.

AFSCME supports the movement of residents to smaller facilities when it is the choice of those residents and their guardians and it has been determined that the resident can

receive the appropriate care and services in the new setting. We oppose shifting populations to meet an arbitrary quota or for budgetary concerns. Such sweeping movement of individuals is a recipe for disaster, especially when it is not predicated on the type of individualized planning necessary to make such a move successful.

Even the language frequently used to describe such movement can often be misleading and distort the reality for individuals with developmental disabilities. To say that a resident who is moving from Howe to a smaller setting is moving "into the community" unfairly ignores the reality for many residents and staff that you have heard described by family members today. Particularly for residents who have lived for many years at Howe – it is truly their community and staff is in many ways part of their family. And as the Howe families say, it is the staff that makes Howe a home.

Illinois state-operated developmental centers, as acknowledged in the filing before this Commission, already strive to place residents into community settings, and have transitioned over 300 individuals in the last two years. By the state's own assessment, however, the majority of current residents at Howe will find community setting services and supports inadequate to meet their needs. The state's working estimate is that roughly 243 of the 318 current Howe residents will continue to rely upon services offered in a state-operated congregate center. The State's goal is for 75 individuals to move into smaller settings.

Closing Howe represents a loss of services for the majority of its residents with medical issues, who rely upon access to 24/7 medical care which is unavailable consistently and reliably in a smaller setting.

Closing Howe would also foreclose the possibility of utilizing Howe's cadre of staff psychiatrists, psychologists, and behavior analysts with long experience in developmental disabilities as a resource that could strengthen home and community based services in the region by opening up such specialized services to individuals in residence with their families or in smaller community settings.

As stewards of state funds you must ensure that precious resources are used wisely. Some have argued for closing Howe as a means of freeing up funding to serve more individuals in the community. This argument ignores the well-established principle of economies of scale. Such an argument also ignores that providing more intensive care, services and supports based on the real – and greater – needs of individuals served in congregate centers is reasonably more expensive. Moreover such cost comparisons gloss over the hidden costs in community settings – such as health care – which are more explicit in congregate care. Research that compares total costs in community versus congregate settings finds when all the hidden factors are taken into account there is little savings to community programs and that in fact they can cost more.

In studies that do show a cost differential, the difference is not due to efficiencies in the community but to lower wage levels which increase direct support staff turnover in community settings that in turn drives down quality.

In 2004, in Illinois the turnover rate for direct support staff at state-operated developmental centers was 11 percent. The turnover rate of similar staff in vocational, residential and in-home support settings was 36 percent. The fiscal costs of turnover are significant but are slight in comparison to the emotional toll and the impact on the quality of life for individuals who depend on daily support. Research shows high turnover is a predictor of more injury-related secondary conditions, higher rates of health care utilization and poorer health outcomes.

There are significant costs to closing Howe and other state-operated developmental centers.

When state facilities close, the public investment in experienced staff is lost.

Once sold, the investment in the public assets of the building and valuable property are lost and hard to replace or restore in the foreseeable future. I have seen even the best intentions to build new and improved public facilities lay fallow over years because the promised funds never can be found.

Closing Howe forecloses opportunities for innovative models of delivery and synergies with community services and other populations. For example, keeping Howe open would allow for opportunities to expand dental and medical clinic services, physical therapy, recreational and wheel chair repair services to meet the unmet needs of individuals with developmental disabilities residing close in the catchment area. We would welcome the opportunity to work with the State to develop such innovative and enhanced uses of services at Howe.

The loss of existing services and the divestiture of opportunities to meet unmet demand are particularly troubling during a time of state budgetary crisis.

Experience from other states and jurisdictions are warnings that the closure of state institutions or transfers into community care may not yield the desired or promised results for the former residents or the state agency.

Research on California looked at the some 1,878 residents who moved out of state facilities and to community care. The research found the risk-adjusted mortality rates of the movers exceeded the rates of those in the institutions by 51 percent. After the researchers removed cancer deaths from both groups the difference increased to 67 percent. The effect was largest shortly after the move and in the subjects who moved out most recently.

I understand that a similar mortality pattern occurred during and after the closure of the Lincoln Developmental Center.

The Government Accountability Office, Congress' investigatory agency, has raised concerns with the failure of states to investigate the deaths of individuals with developmental disabilities residing in community settings.

The death of any individual whose care has been entrusted to the State -- whether the individual resides at a congregate setting or in a facility in the community -- is a tragic loss. It should prompt a thorough review to root out any systemic failures or vulnerabilities in the delivery of care that must be corrected and addressed to prevent any similar adverse events and deaths. The fact that the State claims it has systemic failures at Howe that is refuses to redress through re-certification under Medicaid is deeply troubling. It reflects a lack of commitment to address vulnerabilities in the delivery of care or desire to identify systemic weaknesses that need correcting to prevent problems in care.

Much has been made of Illinois' low ranking in providing services and supports in smaller settings as compared to other states. But the ranking does not tell the full story. In 1991, the District of Columbia was the first jurisdiction to transform its system to be entirely based on community services – not a single institution. An advocacy-based lawsuit prompted the closure of Forest Haven and led to the dispersal of its 1,100 residences to a new community-based system that would provide more individualized care in homelike settings. The lawsuit is still ongoing and the reform is widely regarded as an abject failure. I have previously submitted to COGFA a news series reported in the *Washington Post* that describes the chilling cases of deaths, abuse, neglect and molestation or stealing in the group homes and day programs perpetrated on the residents of the promised homelike care.

The problems in DC are a warning to those who see an either/or policy war between state centers and other settings.

Before the Department of Veterans Affairs (VA) decided where new facilities should be built or where others should be downsized, or realigned to be centers of excellence, a rigorous data-driven planning process occurred with the involvement from a broad range of stakeholders.

I encourage you to consider whether closing Howe is the best option to serve current residents. Is it the best option to leverage enhanced services for those who reside with family and need recreational services, dental care, respite care, wheel chair repair and other services which could be provided through Howe to the community? Will shutting Howe increase the state's level of individual supports needed to reduce the growing waiting list of individuals in need of critical and emergency services? Will it build the state's capacity to serve the needs of a currently aging population of individuals with developmental disabilities?

Keeping Howe open does not block the movement of the estimated 75 individuals into other settings, but closing Howe stifles many opportunities for innovation and expansion of services—and puts all of its residents at risk of emotional and even physical trauma.

Instead of closing Howe to quickly facilitate a land sale that given the fiscal problems in the state may not benefit individuals with developmental disabilities, I urge you to reject the closure proposal and support a planning process that looks at the current and long-term needs of residents of state operated centers, the role of the centers, and opportunities for enhanced and expanded services. Until that process is undertaken, closing Howe presents too much risk.

I have devoted most of my remarks to Howe Center, but I want to address one aspect of the plan to close Tinley Park Mental Health Center. The Tinley plan calls for privatized management of the facility by July 1, 2009, and likely a fully privatized facility when newly constructed. This is not a national trend, it is very uncommon nationally. The recent announcement by Georgia that it intends to privatize its system was met with skepticism by advocates and community providers. I have previously submitted an article from the Atlanta State Journal Constitution that notes such privatization is rare in other states and has met with mixed results.

I understand that the State seems to have little sense of what they want out of such a system. My experience with the VA and the Federal Government is that at best you get what you ask for with a private contractor. If you don't have clear standards of performance and measureable, meaningful quality outcomes you will not get them.

When the government privatizes services it loses control over the delivery of care and staff. There is a reduced, diverted and tangential accountability for quality and costs. Unfortunately, when problems do occur in the public's mind it isn't the contractor's fault but the state agency who relinquished its control over staff, costs and quality but not responsibility.

I urge this Commission to send a strong signal to the Governor that the public hospital serves a specific need, was requested by task force, and is the best model for care.

# Vision and Plan for the Replacement of the Tinley Park Mental Health Center

Illinois Department of Human Services
Division of Mental Health
Lorrie Rickman Jones, Ph.D., Director
December 11, 2008

# Tinley Park Mental Health Center
# Renaissance Plan

## What is the plan, in summary?

- The Department of Human Services (DHS) announced a plan to replace the Tinley Park Mental Health Center (TPMHC) with a new, state-of-the-art hospital
- The plan provides an opportunity to improve the quality of care and safety of persons with mental health needs throughout the Southland area
- The plan has been and will continue to be framed by the strategic involvement of stakeholders including consumers, families, mental health advocates, providers and more

# Tinley Park Mental Health Center
# Renaissance Plan

## DMH mission: the Mental Health Authority

- DMH operates nine hospitals statewide
- TPMHC is regionally responsible for DHS Region 1 South, which includes the far South Side of Chicago and southern Cook, Will, Grundy, and Kankakee counties

Goal: Part of strategic vision for hospitals to be Centers of Excellence where consumers receive:

- Specialty care and treatments for 'hard to treat' issues
- Evidence-based care and services
- Leading-edge recovery-focused, trauma-informed care
- Access to inpatient acute care in support of community hospital overflow

# Tinley Park Mental Health Center
# Renaissance Plan

## What is the current environment?

- In February 2007, TPMHC was decertified by Center for Medicare Services (CMS), and later placed on preliminary denial of accreditation by The Joint Commission (JCAHO)
- TPMHC has since been re-accredited by JCAHO; however, is still awaiting its CMS survey for recertification
- As a result of its decertification status, TPMHC currently cannot bill the federal government for Medicare and Medicaid services
- TPMHC continues to have significant "life safety" concerns directly related to the physical plant
- TPMHC continues to experience difficulties recruiting and retaining professional staff

# Tinley Park Mental Health Center
# Renaissance Plan

## What are the details of the process?

- Vacates all but two of existing TPMHC buildings, July 1, 2009
  - Leverages most opportunity towards land sale
- Locates all mental health services into existing Maple Building
  - Consolidates care delivery and creates cost efficiencies
- Maintains hospital operations on the campus until the replacement hospital is built (2012)
  - Upholds 2005 commitment to stakeholders
- Contingency preparations for use of other Chicago area hospitals as may be needed
  - Fluidity of response to meet any possible changes

# Tinley Park Mental Health Center
# Renaissance Plan

## What is your process and timeframes?

- Through an RFI published November 3rd, determined vendors' interest and received more information to frame an RFP
- Through a single RFP posted in early 2009, transition TPMHC management staff to private vendor by July 2009
- Through a single RFP posted in early 2009, award vendor to plan with DMH and construct new hospital for 2012 occupancy
- Assist awardee with Certificate of Need as co-applicant in late spring 2009

# Tinley Park Mental Health Center
# Renaissance Plan

## What will the vendor do?

Vendor award is planned to include three deliverables:

- Vendor assumes administration and management of existing direct care staff at the existing TPMHC beginning July 2009 under a purchase of care contract
- With DMH, vendor will design, plan, finance and construct the new hospital on publicly owned land
- Under a purchase of care agreement with the state, vendor will assume full administrative control of hospital & staff as stated in the RFP

# Tinley Park Mental Health Center
# Renaissance Plan

## Why bring in an outside vendor?

- State-of-the-art information management technologies e.g. electronic medical records, real time order entry system, quality management and inventory control technologies
- Enhanced ability to recruit, attract, hire and retain highly qualified senior clinical and management staff
- Innovative private sector ideas can be introduced into public system
- Quick, nimble and flexible enough to respond to state and community needs
- Continuous quality improvement and shared "best practices" to enhance the entire system
- Capitated fixed-rate contract

# Tinley Park Mental Health Center
# Renaissance Plan

## How will the vendor be managed?

- Vendor will be integrated into DMH administrative team
- DMH will monitor specific contract deliverables including but not limited to:
  - Treatment outcomes that reflect person-centered care
  - Quality indicators
  - Consumer satisfaction
  - Compliance to regulatory standards
  - Admission accessibility
  - Length of stay
  - Recidivism rates
  - Staff retention and vacancy rates

# Tinley Park Mental Health Center
# Renaissance Plan

## Public-private partnership

Based on the state's experience

- Efficiencies result in increases of
  - Quality of care and consumer satisfaction
  - More persons served
  - Staff productivity and retention
  - Timely Medicare/Medicaid claiming
- Efficiencies result in reduction of
  - Personnel and overtime usage costs
  - Maintenance, supply and housekeeping costs
  - Pharmaceutical and outside medical costs

# Tinley Park Mental Health Center Renaissance Plan

## What has DHS done to prepare for this action?

- ☐ Weekly meetings to track issues and maintain timelines
- ☐ Site visit to assess other state's projects
- ☐ Preliminary visits for site determination
- ☐ Completion of RFI and its publication
- ☐ Completion of CGFA report and its publication
- ☐ Meetings with:
  - CMS, CDB and HFPB to inform and receive input
  - Regional providers and Illinois Hospital Association
  - Employees and staff, as well as union leaders
  - Consumer advocates including state and local NAMI affiliates
- ☐ Posted information on DHS Web site
- ☐ Media briefings

# Tinley Park Mental Health Center
# Renaissance Plan

## Why now?

- Builds on community stakeholder planning that began in 2004 and concluded a need for a new hospital
- Meets immediate need to upgrade/replace/vacate failing infrastructure
- Supports Southland growth and demand for services
- Leverages opportunity to advance current technologies and recovery-focused care
- Leverages opportunity with sale of Tinley Park land to reinvest proceeds into MH/DD services
- Leverages Howe recommendations

# Tinley Park Mental Health Center
# Renaissance Plan

## Why now?

- JCAHO accreditation is current; but certification by CMS (feds) is still pending
- Several life safety and building issues are recurring, costly and potentially insurmountable
- Fixes of these safety issues are temporary, likely will need greater modification and cost in the future as regulatory and accreditation standards increase over time
- We need to rise above standards, not just maintain minimum compliance

# Tinley Park Mental Health Center
# Renaissance Plan

## Why not keep things as they are?

- TPMHC sits on 126 acres with 21 buildings; TPMHC actively uses 2 buildings and shares use in another 3; Without Howe, this can be reduced to 2
- Maintaining a TPMHC-Howe campus of more than 300 acres with as many as 38 vacant buildings, many uninhabitable, is inefficient
- The current campus has 85-90% more land than TPMHC needs
- If Howe closes, maintaining campus as is would require increasing TPMHC headcount by 32 and $3.2 million for power plant and ground maintenance alone
- Reduces state long-term obligation for maintaining buildings, grounds and infrastructure

# Tinley Park Mental Health Center
# Renaissance Plan

## Won't this be burden to consumers?

- During the transition years and until new building occupancy, consumers should notice little change –units will remain the same; relationships with local hospitals and agencies will remain intact
- The date of occupancy into the new building is the ONLY time when some consumers might actually be moved from one locale to another site
- Upon occupancy, the difference will be a new, state-of-the-art hospital offering quality and safety benefits that cannot be achieved at the present site.

# Tinley Park Mental Health Center
# Renaissance Plan

## Conclusion

- Quality and safety of care strengthened
- Alignment with best and evidence-based, recovery-oriented, person-centered practices
- Consumer- and family-centered care environment
- Maximizing professional opportunities for staff
- Effective use of state dollars
- Investment in the Southland
- Reduces state long-term obligation for maintaining infrastructure

# Tinley Park Mental Health Center
# Renaissance Plan

## Thank you!

- Comments and questions

**Illinois Association of Rehabilitation Facilities (IARF)**

# Written Testimony
## Commission on Government Forecasting and Accountability
### Meeting Re: Proposed Closure of Howe Developmental Center and Tinley Park Mental Health Center

**December 11, 2008**

HOWE STATE OPERATED DEVELOPMENTAL CENTER:

The Illinois Association of Rehabilitation Facilities is a statewide association representing over 90 community agencies that provide services and supports to persons with disabilities, mental illness, and substance abuse problems in the community. We appreciate the opportunity to go on record regarding the proposed closure of Howe State Operated Developmental Center.

We have been following with interest and concern the downward spiral of events that have occurred at the Howe State Operated Developmental Center in recent months and years and have concluded that closure of this facility is in the best interest of the residents and is in keeping with more contemporary methods of providing support for persons with the developmental disabilities. The State has invested millions of dollars on consultant contracts in an attempt to correct the dysfunction at Howe and provide safe and quality supports to its residents and peace of mind to their families and guardians but those efforts have failed. It has invested millions of General Revenue Funds after Howe was decertified by the federal Centers for Medicaid and Medicare. It is time for the State of Illinois to provide the leadership and financial support to move this process forward and to adequately invest in the full support of individuals who transition into the community setting of their choice.

While closure is clearly the right choice we know that the process must be thoughtful, carefully planned, transparent to all, respectful of the choice and preferences of the individuals transitioning to community settings, is adequately funded and that the network of community providers who will now be providing that support are appropriately funded. There are examples from many other states that have successfully made this transition and we hope that such experience is utilized. If IARF can be of assistance in providing such examples to the Commission we would be more than happy to do so.

**It is absolutely essential that the resources necessary to provide the appropriate supports for individuals with developmental disabilities in a community setting is made available. Without adequate financial support and adequate rates to support individuals with intensive needs you risk the failure of this transition and the disruption of lives. In short you risk failure.**

What do we mean by adequate resources?

- It means making quality medical, dental, psychiatric and general health care accessible to those making the transition to community supports.

- It means providing a rate of reimbursement that appropriately funds the supports required by individuals during the transition phase and for the long term.

- It means wages and benefits that create incentives for quality support staff to stay in the field and provide the dependable support and consistent personal relationships so essential for quality of life.

- It means support for adequate housing in the community.

- It means the system may have to move from "one size fits all" to a system nimble enough to flex with the evolving needs of the individuals who are being supported in the community, who want different things at different points in their lives, who age, who want friendships, social networks and a full and meaningful life.

- It means nothing less than significant systems change, including the way supports for individuals with developmental disabilities are prioritized and funded in Illinois.

It will require focused and responsive leadership from the Department of Human Services, the Office of the Governor and the General Assembly to achieve the outcome desired - a vibrant, flexible and fully funded system of supports for individuals with developmental disabilities, no matter what their level of disability. It means a system designed to support them for life.

IARF stands ready to provide input, support and assistance wherever we can to achieve success in this process.

TINLEY PARK MENTAL HEALTH CENTER:

Individual with disabilities, family members, and professionals recognize that integrated programs are the preferred setting for nearly all people with mental illness. The vast majority agree that most individuals with mental disabilities – even those with severe mental illness and complex needs – can live successfully in community settings. Furthermore it is a requirement of the ADA, and the Supreme Court decision (Olmstead v. L.C.) gives legal weight, that states must administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.

IARF believes a strong and diverse community system supported by a network of emergency services and crisis residential options is a reasonable and practical alternative to institutionalization of persons with mental illness. The Associations supports downsizing and/or closure of state hospitals but only if the following takes place:

- A proper community infrastructure must be in place to support those individuals utilizing the state facility.

- A plan to redirect funding of the state hospital to the community system that will be required to support those individuals that would otherwise be residing in the state hospital proposed for closure. It is critical that funding currently utilized to support each state hospital remain

within the budget of the Department of Human Services (DHS) for use in community operations.

- Psychiatry must be available in adequate capacity to meet the needs of this population and should be subsidized out of DHS funds – given the inadequacy of DHFS physician rates.

- Affordable Housing Supports such as Section 8, group homes and supported living must be available.

- The linkage between the community mental health centers and the community hospitals must be further developed in closure areas (i.e. emergency services, crisis residential, case management, linkage/aftercare, psychological testing, and forensic specialists). Where these services and/or facilities are not available, closure funding should be made available for development.

Persons with serious mental illness can and should be treated in the community. However, planning and adequate investment in community mental health services must be in place in order to achieve the desired outcome. Communities will be set up to fail without proper supports in place.

IARF stands ready to provide input, support and assistance wherever we can to achieve success in this process.

Janet S. Stover
Executive Director
(217) 753-1190

Advancing the human and civil rights of people with disabilities
SELF-ADVOCACY ASSISTANCE ★ LEGAL SERVICES ★ DISABILITY RIGHTS EDUCATION ★ PUBLIC POLICY ADVOCACY ★ ABUSE INVESTIGATIONS

December 9, 2008

The Honorable Jeffrey M. Schoenberg, Co-Chairman
The Honorable Richard P. Myers, Co-Chairman
State of Illinois Commission on Government
Forecasting and Accountability
703 Stratton Office Building
Springfield, Illinois 62706

Dear Senator Schoenberg and Representative Myers:

Enclosed please find our written comments in support of the Department of Human Service's plan to close the Howe Developmental Center and the Tinley Park Mental Health Hospital. We appreciate the opportunity to present our written comments and to answer any questions the member of the Commission may have regarding the conditions that have led to the proposed closures.

Sincerely,

Zena Naiditch

ZN:dwt

Enclosures

# EQUIP FOR EQUALITY'S COMMENTS IN SUPPORT OF THE STATE'S DECISION TO CLOSE THE HOWE DEVELOPMENTAL CENTER AND THE TINLEY PARK MENTAL HEALTH HOSPITAL

Equip for Equality strongly supports the decision by the Department of Human Services to close the Howe Developmental Center and the Tinley Park Mental Health Hospital. Equip for Equality first called for the closure of the Howe Developmental Center on February 7, 2007, following onsite investigative activity, which revealed the existence of very serious problems placing the health and safety of those living at Howe at significant risk.

Equip for Equality is an independent not-for-profit organization designated by the Governor in 1985 to administer the federal Protection and Advocacy System for people in Illinois with physical or mental disabilities. Equip for Equality's mission is to advance the civil and human rights of people with disabilities and is accomplished through self-advocacy training and technical assistance, legal services, and public policy initiatives. In its capacity as an independent watchdog, Equip for Equality also conducts unannounced on-site monitoring visits to programs and facilities across the state and engages in systemic investigations to address abuse and neglect of people with disabilities.

Closing these institutions is absolutely the correct decision not only for the people with disabilities residing there but also for the taxpayers of Illinois. Millions upon millions of taxpayer dollars have been spent supporting these two State-run institutions that were decertified from the Medicaid program more than 18 months ago resulting in the loss of an extraordinary amount of matching Medicaid dollars for Illinois.

Closing the Howe Developmental Center will allow people with developmental disabilities to leave a dangerous institution and to choose where and with whom they wish to live and receive quality services in the most integrated setting. Closing Tinley Park Mental Heath Hospital will allow the Department of Human Services Division of Mental Health to build a new state of the art mental health facility in the same geographic area to meet the needs of people with serious mental illness for acute care. It is critical that the Department proceed with these closures in a timely and appropriate manner.

**Investigation of the Howe Developmental Center:**

Since the fall of 2006, Equip for Equality's Abuse Investigation Unit has been engaged in an ongoing in depth investigation into the conditions at the Howe Developmental Center. The investigation to date has encompassed more than 1,500 hours of staff time, involving numerous site visits, interviews, the review of hundreds of records, examination of every death and eight investigative reports describing in gruesome detail 21 of those deaths and multiple instances of care that was nothing short of abysmal. Four additional deaths, revealing the same kinds tragic consequences resulting from staff failures, have occurred since the eight reports. Copies of the reports are attached to these comments.

The findings of the Investigation Unit reveal the same kinds of horrific care that led Medicaid to decertify Howe from that program in the spring of 2007, resulting in the loss of more than 50 million dollars of matching Medicaid funds for Illinois. The Investigation Unit's findings also led to the initiation of an investigation by the United States Department of Justice into violations of the Constitutional rights of the people living at Howe. The following two deaths, which the Investigation Unit examined, illustrate the kind of abysmal treatment that the people living at Howe have been forced to endure for years:

- An individual with profound mental retardation and cerebral palsy, who used a wheelchair, was at risk of developing decubiti, (bed sores). Accordingly, doctors ordered that staff change his position every two hours. During an early evening, staff noted that the individual, who had been sitting in his wheelchair in the living area of the unit for several hours, appeared unresponsive. Direct care staff determined that the individual was not breathing and that he did not have a pulse. Rather than administering CPR, as staff had been trained and certified to do, staff called for help and let the responding nurse initiate CPR. Clinical records revealed that he sat in his wheelchair without a change in position for nearly 5 hours before staff discovered that he was no longer breathing and unresponsive. Paramedics arrived shortly thereafter and found that rigor mortis had already set in demonstrating that the individual had been sitting in his wheelchair dead for several hours during dinner and the early evening while in the presence of staff and the other individuals living in the unit.

- An individual, who was profoundly mentally retarded, blind, non-verbal and with significant heart disease, required anti-anxiety medication before undergoing medical procedures to ensure that she would remain calm during those procedures. Staff was aware that the medication was required and that when given, the individual could calmly and safely undergo various procedures, including dental procedures, mammograms and pap smears. Prior to an unscheduled pap smear, direct care staff and medical staff failed to give the required anti-anxiety medication. The individual was forced nonetheless to undergo the Pap smear. The individual struggled through out the Pap smear; so severely did she struggle that multiple staff had to hold her down on the bed by her hands and legs in order for the doctor to be able to complete the procedure. The individual remained extremely upset even after the procedure was finished. Within one within an hour of the Pap smear, she collapsed and died.

Howe's longstanding serious problems include the failure of direct care and medical staff to implement even basic and fundamental care in such areas as:

- Failure to initiate CPR promptly
- Failure to adequately respond to pain
- Failure to ensure that individual receive enough to eat and drink
- Failure to ensure adequate hygiene by leaving individuals in urine soaked clothing

- Failure to reposition individuals to prevent bedsores and other skin breakdown
- Failure to monitor vital signs
- Failure to implement doctor's orders
- Failure to promptly obtain medical referrals
- Failure to adequately address self-injurious behavior
- Failure to provide adequate 1:1 supervision resulting in injuries
- Failure to provide adequate medical assessments
- Failure to have individuals examined by a doctor following injuries
- Failure to appropriately address behavioral issues
- Failure to provide meaningful active treatment and appropriate programming
- Failure to report allegations of abuse

Before reaching a decision to close Howe, the State expended hundreds of thousands of more dollars on outside consultants hired to "fix" Howe. Other extraordinary measures taken by the State to fix Howe, including independent monitors, redeployment of staff from other state run institutions to Howe and contract nurses, have failed to keep people from dying or to improve the institution. Not even a single unit at Howe could be sufficiently improved for the Department to seek Medicaid recertification.

It is unconscionable that, given the hundreds of thousands of dollars infused into Howe to improve the standard of care, which clearly have been wasted, in addition to the millions of dollars paid by the State to support a decertified facility, there are those who continue to demand that special interests be placed above the interests of the people the State is supposed to be serving at Howe. Taking any action that would allow a facility that is both dangerous and so fundamentally flawed that it cannot even obtain Medicaid certification is a gross misuse of public funds and an extraordinary risk to vulnerable people. Loss of Medicaid certification would result in the closure of a private facility serving people with disabilities. Subjecting people with disabilities in state-operated institutions to a lesser standard is abhorrent.

While the extent of the problems uncovered at Howe stand out as some of the worst among the state developmental institutions, it needs to be recognized that the nature of the problems at Howe are documented time and time again in other state-run institutions in Illinois and across the country. These are the same problems that Equip for Equality documented at the Lincoln Developmental Center which led then Governor Ryan to close that institution in 2002. The Investigation Unit's examination of problems in other provider settings, including community-based programs, has not revealed the existence of a culture so entrenched within the setting that it is not amenable to change. Nor has that examination revealed the egregious conditions and depth of longstanding problems so plainly evident at Howe.

Moreover, the State's continued reliance upon institutions to serve people with developmental disabilities is outmoded and contrary to federal law. Most states rely much more heavily upon community settings than Illinois to provide services to people with disabilities. Illinois currently ranks last in the country in serving people with developmental disabilities in small community settings. Additionally, the Americans

with Disabilities Act (ADA) and its implementing regulations provide that people with disabilities are entitled to live in the most integrated setting. The United States Supreme Court affirmed this important principle in *Olmstead v. L.C.* holding that unjustified institutionalization is discrimination under the ADA. Closing Howe will not only eliminate the perpetuation of a dangerous facility, but also allow Illinois to reallocate significant resources to support people with developmental disabilities in integrated community settings.

**Ensuring a successful closure process and transition:**

Equip for Equality will work with the State to meet its obligation to ensure the development of a successful transition plan for each person living at Howe that will provide a full array of meaningful choices for people with disabilities and their guardians as to where they will live and the services they will receive and that sufficient resources are made available for those choices. Equip for Equality will provide assistance to people with disabilities and families from Howe to ensure that they are provided with high quality choices that can meet each person's unique needs and preferences so they can enjoy a stable, safe and fulfilling life in the most integrated setting, and that any savings realized through the closure of Howe should be used to provide community services to other people with developmental disabilities.

Equip for Equality will also work with the State to ensure that the plan for the closure of the Tinley Park Mental Health Hospital includes adequate funding so that a sufficient level of acute care mental health services are readily available in the Tinley Park catchment area to meet the needs of individuals with mental illness and, any savings realized through the closure of Tinley Park Should be used to provide community services to people with mental illness.

It is imperative that this Commission recommend that the closure of the Howe Developmental Center and the Tinley Park Mental Health Hospital proceed as planned so that Illinois' citizens with developmental disabilities and mental illness can live and receive services in a setting of their choice where they will be safe and able to lead successful and fulfilling lives, and so that a state of the art facility can be made available to people with mental illness to provide acute care that will enable them to succeed in process of their recovery.

Advancing the human and civil rights of people with disabilities
SELF-ADVOCACY ASSISTANCE ★ LEGAL SERVICES ★ DISABILITY RIGHTS EDUCATION ★ PUBLIC POLICY ADVOCACY ★ ABUSE INVESTIGATIONS

February 6, 2007

Governor Rod R. Blagojevich
Office of the Governor
100 West Randolph Street, Suite 16-100
Chicago, Illinois 60601-3220

Dear Governor Blagojevich:

Equip for Equality's Abuse Investigation Unit has been closely monitoring incidents and deaths that have occurred at the Howe Developmental Center through site visits and by reviewing a substantial number of clinical records. As a result of the findings of the Investigation Unit, together with the serious deficiencies cited by the Department of Public Health resulting in the pending decertification proceedings, **we call upon the State to immediately begin the process of closing Howe Developmental Center**.

**Since September 2005 at least 8 individuals have died at Howe due, in part, to a substantial lack of appropriate care**. The same kind of substandard care was glaringly apparent during a December 2006 review of approximately 10% of the clinical records of individuals currently residing at Howe. Given the extent to which such substandard care is tolerated and embedded within the culture of the facility, it is clear that every individual residing at Howe is at substantial risk of serious injury or death.

Howe's failure to adequately address the very serious deficiencies found by the Department of Public Health (Addendum 1) resulted in not only the need for independent monitors to protect the health and safety of the individuals there but also the initiation of decertification proceedings to remove the facility from participation in the federal Medicaid program. **Such extraordinary action by the Department of Public Health clearly supports our conclusion that this facility must be closed.**

**Recommendations**

We call upon the State to immediately develop an effective plan for the closure of the Howe Developmental Center that includes:

- **A prohibition on any new admissions** into Howe;
- **A transition plan** that will allow for individuals with developmental disabilities and their guardians to identify individual support options in the community to meet their wants and needs;

- **An expansion of the community based service delivery system** to meet the needs of individuals with developmental disabilities as a result of the closure of Howe and the transition to new settings; and

- **Enhanced funding** to allow community service providers to meet the needs of the individuals transitioned into new settings.

An addendum describing fully the our findings of the Abuse Investigation Unit at Howe is attached. We are available to meet and answer any questions you may have or to assist in the development of a closure plan.

Sincerely,

Zena Naiditch
President and CEO
Equip for Equality

The Arc of Illinois

Don Moss
Executive Director
United Cerebal Palsy
of Illinois

The Institute on Disability
and Human Development
at the University of
Illinois at Chicago

cc: Louanner Peters
Deputy Governor – Office of the Governor

Secretary Carol Adams
Illinois Department of Human Services

Dr. Eric Whitaker
Illinois Department of Public Health

Grace Hou
Assistant Secretary – Illinois Department of Human Services

Enclosure

# ABUSE INVESTIGATION UNIT ADDENDUM

## Abuse Investigation Unit Death Reviews

The clinical records related to the individuals who have died demonstrate the degree to which direct care, nursing and medical staff failed to implement even basic and fundamental measures of care in the following categories:

- Failure to initiate CPR promptly
- Failure to adequately respond to pain exhibited by individuals
- Failure to ensure that individual receive enough to eat and drink
- Failure to ensure adequate hygiene by leaving individuals in urine soaked clothing
- Failure to reposition individuals to prevent bedsores and other skin breakdown
- Failure to implement adequate plans to address risk of skin breakdown
- Failure to monitor vital signs
- Failure to adequately monitor bowel activity
- Failure to implement MD orders
- Failure to promptly obtain medical referrals
- Failure to adequately address self-injurious behavior
- Failure to provide adequate 1:1 supervision resulting in injuries
- Failure to provide adequate medical assessments

Failure to provide such basic measures of care can lead to disastrous and swift consequences for individuals with developmental disabilities as illustrated by just two of the recent deaths at Howe described below:

- During the early evening, staff noted that an individual with profound mental retardation and cerebral palsy appeared to be unresponsive in his wheelchair that had been placed several hours earlier in the living area of the unit. Direct care staff in attendance discovered that the individual was not breathing and that he did not have a pulse. CPR was not administered by direct care staff even though staff was trained and certified to do so. Staff called for help and let the responding nurse initiate CPR. Such failure was hardly the first lapse in care provided to this individual. The previous month a doctor ordered staff to monitor the individual's vital signs every shift for 72 hours. The clinical record contained no indication that this monitoring was ever performed. Additionally, because the individual used a wheelchair and was at risk of developing decubiti, (bed sores) doctors ordered that staff change his position every two hours. On the evening of his death, clinical records reveal that he sat in his chair without a change in position for nearly 5 hours before staff discovered that he was no longer breathing and unresponsive. Paramedics arrived shortly thereafter and found that rigor mortis had already set in demonstrating that the individual had been sitting in his wheelchair dead for several hours during dinner and the early evening while in the presence of staff and other residents.

- Another individual with profound mental retardation and epilepsy died following a particularly egregious series of nursing assessments. Shortly before his death, direct care staff documented at least 7 loose stool episodes within a 3-hour span of time. Nursing staff was informed and in response, conducted an assessment during which the nurse noted an additional loose stool but documented that the assessment was otherwise unremarkable. While the nurse noted tremors, all vital signs were documented to be normal. No follow up assessment was conducted for nearly 12 hours when a nurse documented "no apparent distress." The nurse took vital signs and documented that the individual's vitals were normal. Twenty minutes later, a doctor's assessment found that the individual had a temperature of nearly 104, his blood pressure was falling, his abdomen was distended and he exhibited signs of severe dehydration. The individual was immediately sent to a local emergency room, admitted to the hospital and died a short time later.

**Abuse Investigation Unit Clinical Record Reviews**

A December 2006 review of the clinical records of 39 individuals who are wards of the Office of State Guardian all revealed evidence of the same kind of substandard care that the individuals who died received at Howe prior to their deaths. The issues identified can broadly be grouped into the following categories:

- Inadequate Health Monitoring:

Each of the records contain multiple examples of Howe nursing staff failing to carry out MD orders with respect to health monitoring in the form of measurement of vital signs (16 instances) and completion of neurochecks (3 instances) or Howe's "head injury protocol" (2 instances). It should be noted that in100% of the records reviewed that contained an order related to vital signs, neurochecks or head injury protocol there was not documentation to suggest that staff appropriately provided the required assessment.

- Inadequate medical care/medical assessments:

Several charts contained examples of treatments and medication being ordered by an MD without any documentation or assessment by the MD justifying the order. A medical exam for one individual revealed a finding of occult blood without further follow up or evaluation. Another record revealed an absence of any MD documentation for the months of July, August, September, October, November, and to December 14 of this year. Another individual's chart revealed medication orders for Robitussin and Monistat but no MD evaluations were performed. Another individual had a seizure, but evidence of an evaluation by an MD could not be found on the seizure report form.

- Inadequate nursing assessments:

Assessments of one individual following complaint of loose stools did not include an assessment of bowel sounds and hydration status. Nursing staff documented a temperature of 100.2 with no follow up assessment for more than 24 hours. RN

assessments for individual following treatment for bronchitis failed to include an assessment of his lung sounds. The chart of another individual being treated with antibiotics for cellulitus did not reveal any nursing assessments of progress during the time of his treatment. Nursing assessments for another individual failed to address lung sounds despite treatment for bronchitis. Another individual who was given medication for pain had no evaluation of the effectiveness or continued need for the pain reliever. Another individual was given Ativan (a powerful antipsychotic medication) without documentation of his response to the medication or his vital signs until nearly 24 hours later.

- Inadequate Bowel Monitoring:

Numerous charts revealed that staff failed to address the lack of bowel activity for various individuals that extended for more than three days in spite of doctors' orders to the contrary.

- Inadequate Oral hygiene:

Dental assessments of a number of individuals revealed that their mouths were not clean and free of debris and that their teeth were not well brushed. The only individuals who were assessed as having adequate oral hygiene were those who were capable of performing the task independently.

- Failure to obtain referrals:

Doctors' orders for a referral for an eye exam and a dental exam were not timely made.

- Failure to appropriately address behavioral issues:

A number of individual clinical records contain months of documentation indicating that problematic behaviors have continued unabated with no meaningful changes in the behavioral intervention plans.

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March 7, 2007

Governor Rod R. Blagojevich
Office of the Governor
100 West Randolph Street, Suite 16-100
Chicago, Illinois 60601-3220

Dear Governor Blagojevich:

We are renewing the call for closure of the Howe Developmental Center and present for your review, details of the three additional deaths. The quality of the care provided to these individuals and the circumstances surrounding their deaths, represent the same kind of critical failures noted in our prior call for closure of the institution. The most recent deaths, two of which occurred in the last several weeks, again demonstrate that people living at Howe remain at significant risk of dying from the kind of abhorrent care which continues to be rendered – care which is so bad that the State has been required to pay outside nursing consultants to perform such basic medical procedures as taking vital signs. Even with the extraordinary measures that the State has taken to address the very serious problems at Howe, people continue to die.

The records related to the 3 most recent deaths reviewed by Equip for Equality's Abuse Investigation Unit reveal:

**Death 1:** An individual who was profoundly mentally retarded, blind, non-verbal and with significant heart disease required anti-anxiety medication before undergoing medical procedures to ensure that she would remain calm. Staff were aware that the medication was required and that when given, the individual could calmly and safely undergo various procedures, including dental procedures, mammograms and pap smears. In February 2007, prior to an unscheduled pap smear, direct care staff and medical staff failed to give the required anti-anxiety medication but forced the individual to undergo the pap smear during which she struggled continuously, causing staff to hold her arms and legs in order to complete the procedure. The individual remained upset after the procedure was finished and, within an hour of the pap smear, collapsed and died of a heart attack.

**Death 2:** An individual who was severely mentally retarded, had epilepsy, required a wheelchair and was documented to be at high risk of forming blood clots was not provided with adequate activity or physical therapy to promote sufficient blood circulation to prevent blood clots from forming. No evidence of medication to prevent blood clotting could be found in the individual's medical records or any evidence that medical staff monitored the effectiveness of a surgically implanted filter to prevent blood clots from reaching the heart. Several weeks before

the individual's death, staff failed to take vital signs as ordered by a doctor. Several days before the individual's death, stage II decubiti (bed sores) developed on the individual's buttock as a result of limited movement. In September 2006, the individual died suddenly of a suspected blood clot.

**Death 3:** An individual with moderate mental retardation and diagnosed with a mental illness was unlawfully restrained numerous times as no valid physician order was obtained and the individual was not evaluated by a licensed independent practitioner within one hour of the restraint. Valid physician orders were not obtained and assessments were not conducted in spite of the individual's history of hypertension and dangerously elevated blood pressure during restraint episodes. During one such restraint episode, a nursing supervisor's assessment found no undue risk to the individual's health in spite of a blood pressure reading of 180/100. When the individual's blood pressure remained at 180/100, a different nurse requested that the individual be released from restraints but the doctor refused, ordering continued monitoring instead. Even when the individual's blood pressure reached 200/100, the individual remained in restraints. At various times within the 60 days that preceded the individual's death, staff also failed to routinely monitor the individual's vital signs as ordered by a physician even though anti seizure medication, known to have serious cardiac effects, was prescribed for the individual in very large doses and he had high Cholesterol levels. Several months before the individual's death, the interdisciplinary team recommended taking the individual off of Haldol, an anti-psychotic medication, and starting the individual on Depakote, an anti-psychotic medication that the individual had a known allergy to. In December 2006, the individual was diagnosed with severe Osteopenia, but as of the date of death several months later, no medication had been prescribed to address the condition. The individual's chart does not contain documentation of the events immediately preceding the death in February 2007, but hospital records indicate that the individual died of an apparent heart attack.

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We call upon the State to immediately begin the process of closing the Howe Developmental Center and to immediately take all necessary actions to ensure the safety of the individuals living there and prevent further deaths. We are available to answer any questions you may have or to assist in the development of a transition plan as outlined in our February 6, 2007 letter calling for the closure of Howe, an additional copy of which is attached for your convenience.

Sincerely,

Zena Naiditch
President and CEO

cc: Louanner Peters
Deputy Governor - Office of the Governor

Secretary Carol Adams
Illinois Department of Human Services

Dr. Eric Whitaker
Illinois Department of Public Health

Grace Hou
Assistant Secretary - Illinois Department of Human Services

Enclosure

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VIA FACSIMILE and POSTAL SERVICE

March 21, 2007

Governor Rod R. Blagojevich
Office of the Governor
100 West Randolph Street, Suite 16-100
Chicago, Illinois 60601-3220

Dear Governor Blagojevich:

In light of the recent decertification of the Howe Developmental Center, and the Abuse Investigation Unit's most recent observations of staff actions and record reviews, we are again calling on the State to 1) close the facility and to take immediate action to develop a reasonable closure plan to allow for the timely and safe transition of the individuals living at Howe to other settings of their choice; and 2) enhance the level of monitoring to ensure the safety of the individuals living at Howe.

The fact that Howe was unable to meet minimum standards to pass a survey, which by the facility's own admission they prepared for over the course of several months, once again demonstrates the depth of the problems that have continued unabated. The Abuse Investigation Unit's most recent visits to Howe this month confirm the depth of those problems and the urgent need to begin the process of closing the facility. Based upon those most recent visits and information received by this office it is evident that:

- Howe staff are intentionally engaging in conduct designed to create a heightened level of anxiety in individuals living there and their families;
- Individuals continue to be at significant risk as a result of staff's failure to report incidents of abuse and neglect, staff's failure to follow individual plans developed to address specific needs and medical staff's failure to conduct examinations following injuries and incidents;
- Facility records also document that restraints are being used unlawfully and that staff may also be improperly utilizing seclusion.

We call upon the State to immediately enhance the level of monitoring to ensure the safety of the individuals living at Howe while the State takes action to address the future of that institution. We are available to assist in such monitoring activities as we were called upon to do prior to the closure of the Lincoln Developmental Center. We are also available to

answer any questions you or your staff may have and to assist in the development of a closure plan as outlined in our February 6, 2007 letter calling for the closure of Howe.

The closure of the Howe Developmental Center provides the State with an important opportunity to address the significant fiscal inequity in the amount of funds which the State allocates to the community based system of care for people with disabilities in Illinois, a system which is woefully under funded. We call upon the Administration to commit that the savings realized as a result of the closure will be reinvested exclusively in the community system of care.

Sincerely,

Zena Naiditch
President and CEO

cc: Louanner Peters
Deputy Governor - Office of the Governor

Secretary Carol Adams
Illinois Department of Human Services

Dr. Eric Whitaker, Director
Illinois Department of Public Health

Barry Maram, Director
Illinois Department of Healthcare and Family Services

Grace Hou
Assistant Secretary - Illinois Department of Human Services

Enrique J. Unanue
Deputy Director - Office of Health Care Regulation, IDPH

VIA FACSIMILE & POSTAL MAIL

July 12, 2007

Governor Rod R. Blagojevich
Office of the Governor
100 West Randolph Street, Suite 16-100
Chicago, Illinois 60601-3220

Dear Governor Blagojevich:

We are sending this letter to set forth our latest, serious concerns related to the Howe Developmental Center, the safety an care of the individuals residing at that institution and to call upon the State to take immediate action to remedy those problems.

As I am sure you are aware, our staff has spent significant time monitoring conditions at Howe. Despite the very serious problems resulting in the de-certification of Howe, other than this office, we are unaware of any other ongoing independent monitoring at the facility. Given the number of deaths that have occurred and the longstanding nature of the problems that continue at Howe, we believe that it is imperative for the State to have an independent interdisciplinary team of full-time monitors at Howe to ensure the safety of the individuals residing there while the facility remains open.

We are aware of the Department's intent to seek re-certification of Howe. However, the same kinds of serious problems that lead to the deaths of a number of individuals and to the decertification of the facility continue to be plainly evident during each of our visits, including our most recent visit on July 10, 2007, and include:

- Staff misuse of restraint through such devices as lap trays, mitts, and recliners.
- Routine hygiene practices, such as the use of gloves to address infection precautions, sanitizing furniture soiled by incontinence, cleaning feeding pumps, are ignored.
- Individuals warehoused without meaningful programming or activity.
- Individuals engaging in self-abusive and other maladaptive behaviors, including hitting and biting, with no staff intervention.
- Staff reassignments to other units or locations without apparently receiving essential information on the needs of each of the individuals under their care.
- Individuals left alone in living and dining areas of residential units.
- Interactions between staff and the individuals lacking in any clear purpose.
- Storage closets with chemicals, cleaning supplies and other dangerous items left open and unattended.

- A strong odor of cigarette smoke inside a residential unit with medically complex individuals.
- A fire drill that did not result in the evacuation of residential units.

Recent record reviews by our staff continue to reveal the same serious longstanding problems which have resulted in dire consequences for individuals and in the facility's decertification including:

- Failure to provide nursing assessments:

  On 5/22/07 nursing staff was asked to monitor a rash that had developed on an individual. Howe nursing staff failed to document any assessments between 5/24/07 and 6/2/07 where documentation indicates that the condition had resolved.

  A second individual was given 4mg of Ativan for sedation on 6/14/07 without any follow up assessment or monitoring of the individual's vital signs for two days in spite of a large dose of medication to calm the individual in order to undergo a procedure.

- Failure to follow doctors orders:

  On 4-29-07 a doctor ordered that neurological checks be done every four hours following a head injury. Contrary to the order the assessments were documented at 4:38 pm, 11:00pm and 2:30 am only.

  On 6/25/07 a doctor ordered vital signs every shift for 72 hours. Vital signs were not taken on the 25th,were attempted once on the 26th and were not attempted at all on the 27th.

  On 6-1-07 a doctor ordered for vital signs every shift for 72 hours. The chart contained no indication that this was done.

  A doctor ordered that he be notified when an individual's blood sugars were lower than 60 or above 400. The chart contained no documentation indicating that the doctor was notified on 7 occasions when the blood sugars were outside this range:

| Date | Blood sugar level |
|---|---|
| 5-2-07 | 52 |
| 5-4-07 | 41 |
| 5-18-07 | 421 |
| 6-7-07 | 59 |
| 6-19-07 | 51 |
| 6-20-07 | 53 |

- 6-21-07 48

  On 7-1-07 a doctor ordered vital signs every shift for 72 hours; temperatures were not taken as they should have been. On 7-2-07 direct care staff documented that the individual felt warm, nursing staff took his temperature and found it to be 102.5. The resident was promptly sent to the hospital.

  On 3-11-07 a doctor ordered that bacitracin be given for an injury. The chart contained no related nursing assessments, and no follow up by a doctor.

- Lack of Direct Care Staff Documentation:

  No direct care staff documentation between 3-25-07 and 4-26-07 and again between 4-26-07 and 5-29-07 in one individual's chart.

  No documentation for the month of May in another individual's chart.

  No direct care progress notes since February for one individual.

  One chart did not contain any nursing or physician progress notes.

- Lack of consult follow up:

  On 3-22-07 a cardiology consult recommended than an ECHO be performed. The test was scheduled for 6-11-07, but the individual went out on a site visit that day. The ECHO was not rescheduled as of 7-3-07.

  The results of a 3-22-07 TB test was not read within the 72 hour period, but was documented as "negative" anyway.

- Dental Care:

  Oral hygiene regarded as "poor" by a dentist. The dental assessment reflected that the individual's teeth were not well brushed. This individual relies totally on staff for oral hygiene care.

- Weight measurements:

  No weights for one individual were taken for the months of May or June

- Lack of Nursing/Medical follow up:

On 1-9-07 and 2-10-07 direct care staff documented incidents of loose stools for an individual. No nursing or physician follow up assessments were provided.

On 4-11-07 a resident fell and hit his head. A nursing assessment was not conducted for 12 hours. No physician was notified of the injury. No injury report was found in the chart.

On 4-4-07 a nurse conducting an assessment for a cough failed to monitor vital signs and did not assess the individual's lung sounds. The individual was later sent to the hospital.

- Failure to provide effective treatment:

  An individual has been engaging in self-injuries behavior hitting and biting himself since his admission in 1982.

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The problems at Howe are so endemic and engrained within the culture of the institution that the likelihood of significant sustainable change is extremely minimal - yet the risk to the health and safety of every individual living there remains high. It is unconscionable that the State continues to allow its most vulnerable citizens to live under such deplorable conditions. In spite of the Department's stated intent to have Howe recertified, our recent series of observations and reviews document an institution that remains dangerous and that should be closed.

We call upon the State to immediately:

- Implement an independent, interdisciplinary team of full-time monitors to ensure the safety and well being of the individuals residing at Howe while the facility remains open.
- Make available to Equip for Equality all documents and materials related to Howe's recertification efforts to date.
- Notify all guardians that the Department will work with them on an expedited basis to move individuals to other licensed and certified settings of their choice.
- Shift the focus of the Department's efforts away from its futile attempt to save the institution to an effective and appropriate plan for the closure of Howe.

Sincerely,

Zena Naiditch
President & CEO

Deborah M. Kennedy
Abuse Investigation Unit Director

CCs:

Carol L. Adams, Ph.D., Secretary
Illinois Department of Human Services

Grace Hou, Assistant Secretary
Illinois Department of Human Services

Lilia Teninty, Director
IDHS – Division of Devlopmental Disabilities

Inspector General William Davis
Illinois Department of Human Services

Eric E. Whitaker, M.D., M.P.H., Director
Illinois Department of Public Health

Enrique J. Unanue
Deputy Director – Office of Health Care Regulation
Illinois Department of Public Health

Patsy Swan
Developmental Disabilities Section
Illinois Department of Public Health

Director Barry Maram
Illinois Department of Healthcare and Family Services

Alice Holden
Centers for Medicare & Medicaid Services – Region V

VIA FACSIMILE and POSTAL MAIL

October 9, 2007

Governor Rod R. Blagojevich
Office of the Governor
100 West Randolph Street, Suite 16-100
Chicago, Illinois 60601-3220

Re: Howe Developmental Center

Dear Governor Blagojevich:

We are writing again to provide additional information regarding the Howe Developmental Center's continued failure to meet even minimal standards related to the care and treatment of people with disabilities. Clearly, in spite of the significant resources expended by the State to keep Howe open, the futility of that decision is glaringly apparent from Howe's longstanding inability to provide even the most basic care in a competent fashion.

During August 2007, Equip for Equality's Abuse Investigation Unit continued weekly monitoring visits to Howe. These visits included both review of individual charts and restraint records, including the records of two more individuals who have died, and tours of the living and day program areas. Numerous on-going and serious deficiencies in the quality of medical care, programming and safety of the individuals living at Howe were plainly evident during each visit. Significant findings include:

- Failure to provide medical follow up care after problematic test results
- Inadequate programming
- Inadequate nursing assessments
- Poor nursing and physician care and documentation
- Poor bowel monitoring
- Failure to provide needed emotional/psychological care/assessments
- Failure to provide complete Hepatitis B vaccination series
- Improper implementation of behavioral plans
- Lack of meaningful programming/safe care
- Staff unfamiliar with individual needs/programs/names
- Cancellation of on-site programs without adequate cause
- Improper job functions for persons with disabilities
- Failure to address evidence of Malnutrition
- Failure to properly address abnormal EKG
- Failure to follow physician orders for vital signs

- Lack of adequate repositioning
- Poor nursing care of identified skin breakdown
- Dehydration
- Restraint use in violation of state and federal law

The records reviewed by Investigation Unit staff during August reveal the same problems identified during each of the prior visits. These are the same problems cited repeatedly during the last several years by Public Health and are the same problems which led to the facility's de-certification. Most alarmingly, the problems noted again in August are the same kind of problems identified in the records of a number of people who have died at Howe. The State's apparent willingness to allow the safety and well being of people with disabilities to be severely compromised in an effort to preserve jobs in an inefficient, antiquated and dangerous system of care is appalling and must end.

**August Record Reviews:**

Record and chart reviews documented numerous longstanding serious problems, including the following:

Failure to provide medical follow up care:

On March 20, 2007, a physician requested that a CT scan be taken of an individual's abdomen to rule out a bowel obstruction or to identify other bowel related issues. No results of the CT scan could be found in the individual's chart or other information indicating that any follow up assessment was conducted.

In February 2006, a CT scan of an individual's chest led to a physician's order for a scan of the individual's liver to rule out whether something seen on the liver during the chest CT was cancerous or required treatment. In a note attached to a September 2006 individual service plan the need to schedule a liver scan as ordered in February was again identified. As of August 8, 2007, no CT scan of the liver had been scheduled or conducted.

Inadequate programming:

An individual's service plan included a goal for the individual to attend community outings two times every month. While the individual's records did not document any outings into the community, because staff identified one of the individual's favorite activities as eating, a desired outcome was for the individual to go to restaurants as often as possible. At the time the plan was implemented the individual, was and continues to be, on a pureed diet. The records did not contain any plan for staff to accommodate his special dietary needs in a public restaurant.

An individual who has lived at Howe for nearly seven years has a service plan that includes a 17-step hand-washing program with each step of the program having several months to complete. In spite of the fact that in nearly 7 years staff have not taught him to wash his hands, and progress has been limited to completion of only the beginning steps, the same program remains in the service plan.

In an individual's records staff notes indicate that on one community outing, staff "informed [the individual] of all the activities." The individual is both blind and deaf. As the records contained no information documenting the use of a tactile communication system by staff in order to communicate with the individual, it is unclear how staff "informed" her of the activities during the outing.

Inadequate Nursing Assessments:

Following an incident in which a peer hit an individual in the face, a nursing assessment of the injury was conducted. The nurse identified a small cut to the corner of the individual's mouth that was described as being of little concern. Fortunately, the individual had a previously schedule dental appointment for that day. The dentist identified a "gaping" laceration to the inside of the individual's mouth that required medical attention. Following the dental assessment, the individual was sent to the ER for sutures

Poor nursing and physician care and documentation:

An individual's chart reflected an order for PRN (as needed) pain medication. Contrary to accepted medical practice no documentation could be found as to the effectiveness of the pain medication.

Poor Bowel Monitoring:

An individual's chart reflected an order for bowel monitoring. No monitoring or record of a bowel movement was noted in the chart for three consecutive days. Neither a physician nor a nurse addressed this issue nor was any medication was administered as required by Howe policies.

Failure to provide needed emotional/psychological care/assessments:

Following the death of an individual's father, direct care staff accompanied the individual to the funeral services. Direct care staff documented that …."7-15-07 9:15 Family visit [An individual] went to father's funeral today. He took it well. He met a lot [of] his family while there. They were all glad to see him there. They thank[ed] us for bringing him. *He had a good time.*" (Italics added), no grief counseling was offered following the loss, nor was a psychiatric assessment provided. No physician or nursing mental health assessments were conducted. Two day following the funeral, the individual exhibited problematic behaviors.

No record of any attempt to address the behaviors in connection with the loss of a parent could be found in the individual's chart.

Failure to provide full Hepatitis B vaccinations:

An individual was tested for Hepatitis B upon admission in 2002. The test result was negative. Immunizations to prevent the individual from contracting Hepatitis B were started, but not completed as only two of the three Vaccines were given. A test in September 2006 confirmed that the individual has contracted Hepatitis B.

Improper implementation of behavioral plan:

Following a February 2007 administrative review of an individual's service plan, staff concluded that the individual's use of … "cigarettes will not be restricted." While staff were to encourage the individual not to smoke and to follow the agreed upon smoking schedule, but if the individual chooses to smoke, he was permitted to do so. A July 2007 progress note indicated that the individual "became very agitated with staff when told he had smoked his allotment of cigarettes" and refused to allow the individual to smoke.

**Review of June and July Restraint Records**

While restraint incidents overall have decreased some, the restraint incidents that are documented are more frequently done in a fashion which violates state and federal regulations.

The issues with respect to restraint use fall under five broad categories:

- Restraint use without a physician's order/validation
- Restraint use without examination of the person restrained
- Restraint use for convenience of staff
- Restraint use without safety/comfort measures such as offering fluids or restroom
- Potentially false vital signs measurement during restraint

Restraint use without MD order:

In June and July there were at least three incidents in which individuals were placed in a mechanical restraints for 20 or more minutes where there was no physician order authorizing the restraint and no temporary order with subsequent physician validation.

Restraint use without examination of the individual restrained:

In June and July there were at least eleven incidents in which individuals were mechanically restrained and no nursing or physician assessment (personal examination) was conducted.

Restraint use for convenience of staff:

On 7-19-07 an individual was placed in restraints. At 6:30 she was released for dinner. Following her meal she was returned to restraints for an additional hour.

On 7-15-07 an individual was placed in restraints. At 9:20 she was released to take a shower. Following her shower she was returned to restraints for an additional 2 hours.

Restraint use without safety/comfort measures such as offering fluids, restroom:

On 7-22-07 an individual was placed in restraints. Available documentation indicates that no liquids were offered, nor was use of the restroom offered as is required during the restraint.

On 7-14-07 an individual was placed in restraints. The available records do not reflect that vital signs were monitored during the restraint.

On 7-2-07 an individual was placed in restraints. The available record indicates that liquids were not offered, nor was use of the restroom offered as is required during the restraint.

Potentially false vital signs measurement during restraint:

There were four instances in July where documentation indicates that vital signs were taken during physical holds. Such documentation leads to questions of the veracity of the statement as an individual requiring a physical hold would likely be too uncooperative to measure vitals. In the alternative, an individual who is cooperative with vitals during a physical hold probably does not meet the standard for restraint use.

**Facility Tour Findings:**

On site tours of the residential and day program areas of the facility consistently reveal seriously deficient programs and services with little to no activity or interaction between staff and the individuals served including:

Lack of meaningful programming/safe care:

Through out the units staff frequently rely upon television in lieu of structured treatment and programs to meet the needs of the individuals. Baby toys and other items that are not age appropriate or designed to meet the needs or wants of the individuals continue to be observed.

Routinely, feeding pumps are observed with no documentation to demonstrate that the pumps have been cleaned. Rarely were staff seen offering fluids to individuals during hot summer months.

Additionally, in instances where on-site day programs do not operate resulting in the individuals spending the day in their residence, staff are not implementing the programs and services which are supposed to be provided to the individuals in order to meet their needs and wants.

An individual who engages in pica behaviors (the ingestion of non-edible items) was observed "sweeping" the floor with his hands and then licking his fingers and hands without staff attention or awareness.

In a residential unit two individuals were seated in wheel chairs in the dining area. One staff was observed setting the tables for dinner. She was not interacting with the individuals present. One of the individuals was holding a stuffed bunny with one hand while chewing on a sock that he held in the other hand. Staff setting the table did not attempt to intervene.

Staff unfamiliar with individual needs/programs/names:

In one residential unit, the staff member working in the house stated that he was mandated to work overtime following his regularly scheduled overnight shift in another unit and consequently did not know the names of any of any of the individuals nor could he relate anything about their programs or individual needs, likes or dislikes.

Cancellation of on-site programs without adequate cause:

During one of the visits, the on-site day program was closed. Staff indicated that the program was closed because it was too hot. The policy provided by staff to support the closure, Number 904, "Hot Weather Emergencies" did not appear to support the closing of an on-site air-conditioned program. Facility administrators were confused by the cancellation, as they believed that a directive had been given for the program to remain open. Nonetheless, staff closed the program.

**Recent Death Investigations:**

The deaths of two additional individuals at Howe were examined. A review of the records and charts of the individuals, like the eleven others who have died at Howe since September 2005, reveal very troubling information documenting egregious care in the months preceding their deaths including:

**Death 1:**

The records of an individual who died in 2007 reveal the individual was found unresponsive following a cardiac event, CPR was initiated and the individual was transported to a hospital where she was pronounced dead. The individual's records also contain documentation of a physical examination purportedly conducted by one of Howe's physicians six months prior to the death. The examination, as documented by the physician, reveals a very poorly done examination. Numerous basic errors and omissions in the records suggest that the examination may not have been done at all.

In completing the records related to the alleged examination, the physician documented that the individual's hearing was "grossly unimpaired." However, a report of an audiological evaluation in 2005, which was maintained in the individual's chart, documented that the individual had a profound bilateral hearing loss. There was nothing in the records to suggest that the individual's hearing had been restored.

The physician also documented that the individual's dentition (the arrangement of the teeth in the mouth) was in "fair condition." However, a report from a dental examination done one month earlier, which was maintained in the individual's chart, documented that the individual had no teeth.

The physician failed to document any information in the section of the report related to an assessment of the individual's cranial nerve. The physician also failed to note certain laboratory results suggestive of possible malnutrition. Further evidence of malnutrition was documented by the individual's progressive weight loss from 90 to 83 lbs in the 5 months preceding the physical examination, which was not addressed by the physician and which continued until the individual's death 6 months after the physical examination.

The individual's record contained a physician's order for an EKG. Two days after the physical examination was purportedly conducted, an EKG was done. The results of the EKG revealed an "inferior myocardial infarct--abnormal EKG" (heart attack). No record of any medical follow up could be found in the individual's chart. Two subsequent nursing assessments did not address cardiac issue and no records of any follow up examinations, tests or other assessments were contained in the chart.

Physician orders for nursing staff to take and record the individual's vital signs typically called for vitals to be taken every shift for 72 hours. In response to every such order found in the chart, vital signs were taken during some but not all shifts. Similarly, a physician ordered that nursing staff check the individual's neurological functioning every 4 hours during a 12-hour period, along with vital signs. The assessments as ordered were not done.

Progress notes in the individual's chart related to vital signs that were taken document temperature ranges from 95.3 to 97.6 with such swings in temperature noted on different shifts during the same day. In spite of the temperature swings, the individual's vital signs were documented as normal with no follow up to address the issue.

Several months before the individual's death, nursing staff documented a small decubitus ulcer (a bed sore) on the individual's left hip. Follow up assessments to address the individual's ulcer were poorly done. Moreover, orders to reposition the individual to prevent the development of additional ulcers were not followed. On the date of the individual's death, repositioning was not completed every two hours as ordered.

**Death 2:**

An individual suffering from a compromised renal system died in 2007 from acute renal failure. The individual's records revealed that the individual was hospitalized for 19 days in the month preceding his death. Hospital records reveal that at the time of admission to the hospital the individual was severely dehydrated. Following the hospitalization the individual was treated for a severe intestinal infection, which the individual may have contracted at the hospital. While an autopsy was not conducted, it appears that this chain of events, starting with Howe's failure to provide adequate hydration leading to the hospitalization, the severity of the infection, and the compromised state of the individual's renal system may have significantly contributed to the individual's death.

Should you need any additional information from us regarding the matters set forth above or if you or your staff have any questions, please do not hesitate to contact me at 312.895.7314. We look forward to a response to this complaint.

Sincerely,

Zena Naiditch

ZN:dwt

CCs:

Carol L. Adams, Ph.D., Secretary
Illinois Department of Human Services

Grace Hou, Assistant Secretary
Illinois Department of Human Services

Lilia Teninty, Director
IDHS - Division of Developmental Disabilities

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Alice Holden
Centers for Medicare & Medicaid Services - Region V

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December 20, 2007

Governor Rod R. Blagojevich
Office of the Governor
100 West Randolph Street, Suite 16-100
Chicago, Illinois 60601-3220

Re: Howe Developmental Center

Dear Governor Blagojevich:

Between September and mid-November 2007, Equip for Equality's Investigation Unit conducted five on-site investigations that included tours of the facility, review of medical records and review of restraint documentation and conducted three additional investigations of people who have died at Howe. Including these three deaths, at least 17 people have died at Howe since September 2005.

In a span of time covering less than 3 months, during this period of review, the Investigation Unit identified 20 categories of poor or dangerous care and also found evidence of falsified records and documentation. Significant findings include:

- Utilizing restraints when medically contraindicated
- Failure to release from restraints when medically necessary
- Lack of follow up for abnormal conditions/failure to obtain consults
- Failure to follow doctors' orders
- Failure to administer vaccinations resulting in contraction of hepatitis B
- Failure to provide position changes as ordered
- Failure to monitor bowel habits
- Failure to ensure direct support are familiar with the individuals for whom they have responsibility to provide care and treatment
- Absence of active treatment for individuals not attending day program
- Failure to provide self-administration of medication training
- Failure to provide adequate treatment to prevent development of decubitis ulcers
- Failure to provide rehabilitative services
- Failure to provide emergency care
- Failure to obtain medical evaluation
- Failure to obtain consent for procedures
- Absent or inadequate pain assessments
- Failure to investigate possible abuse
- Physician documentation on annual physicals stating that mammograms and pap smears were normal on *male* patients

- Falsified monthly physician examination forms
- Falsification of physician documentation

Our onsite investigations and review of the three deaths demonstrate that the Howe Developmental Center continues to be plagued by the same very serious problems and substantial deficits in care that led to its termination from the Federal Medicaid program in *March*. Given the ongoing nature of these very serious problems, the extraordinary number of deaths that have occurred and the lack of any evidence of sustainable improvement, the State must reconsider its decision to proceed with its recertification efforts. It is simply shameful that the State continues to place vulnerable people at substantial risk while wasting millions of public dollars in order to preserve a dangerous facility that has conclusively demonstrated over and over again that it is incapable of sustainable change.

**September to Mid-November record reviews:**

Dangerous use of mechanical restraints

- An individual, with a known cardiac condition, was restrained. At 9:54 a nurse documented an elevated blood pressure of 151/102. Direct care staff documented the nurse's blood pressure reading as occurring at 10:40, not 9:54. Records indicate that a physician evaluated the individual at 11:54 and documented the individual's vital signs as stable while the individual remained in 5-point restraints. Direct care staff, however, documented that the individual was released from restraints at 11:40. Setting aside the obviously questionable documentation, while the individual's known cardiac condition should have precluded the use of restraints altogether, when an elevated blood pressure was found the individual should have been immediately released.

Lack of follow up for abnormal conditions/failure to obtain consults

- No follow up could be found in the records of an individual who had an abnormal EKG in July 2006. The only additional information in the individual's record related to a meeting conducted in October 2006 regarding the individual's heath and physical history, which failed to reference the abnormal EKG, and incorrectly noted the individual's last EKG, as one taken in May 2004, which was a normal.

- In June 2007, a physician ordered that a consult be obtained to address an individual's renal issues. No consult was provided as ordered.

- A July 2007 order to make an appointment with a dentist for an individual with a cavity was not followed, no appointment was made and the cavity remained untreated.

Absent or inadequate pain assessments

- An individual who is prescribed over the counter pain medication for a confirmed history and diagnosis of dysmenorrhea, painful menstruation, did not receive any pain medication from May through September 2007. During that time no nursing or physician assessments were conducted related to dysmenorrhea or the level of the individual's pain.

- Tylenol was prescribed for an individual for pain management. Staff gave the individual Tylenol one time. The individual's record contains no documentation of any pain assessments or follow up to determine the effectiveness of the pain medication.

- Direct care staff found notified nursing staff about an individual with a nearly torn off toe nail. A nurse conducted an assessment and notified the doctor. The doctor did not examine the individual's toe for two days and then ordered Tylenol for pain. Howe nursing staff failed to provide any pain assessments during those two days and no pain medication was provided to the individual during those two days.

Failure to follow doctor's orders

- Staff failed to follow doctors' orders to take and monitor two individual's blood pressure, respiration, pulse and temperature, vital signs, every shift for three days.

- Following two separate head injuries, staff failed to implement doctor's orders to follow facility head injury protocol to assess the individual's condition each shift for 72 hours. Following one injury, the individual was assessed one time during the 72 hours. No follow up assessment was conducted in response to the other individual's injury.

Seroconversion of Hepatitis B

- An individual who was admitted to the facility in 1975 free of Hepatitis, subsequently tested positive for Hepatitis B.

Failure to provide position changes as ordered

- Review of numerous records reveals ongoing failure to follow repositioning orders for many individuals who are at risk of developing decubitus ulcers (bed soars). The failure to follow this simple order can have significant and dire consequences for people. Decubitus ulcers are not only very painful, they expose the individual to infection, sometimes leading to death, and are difficult to heal.

Physician documentation on annual physicals stating that mammograms and pap smears were normal on male patients

- Following annual physical examinations, physicians complete reports related to their findings. In two instances, the physicians prepared reports for two *male* residents indicating that the residents` mammograms and pap smears were "within normal limits".

Failure to ensure direct care staff is familiar with individuals

- During a site visit to a residential unit, Investigation Unit staff inquired about an individual with evidence of an injury. In response, direct care staff indicated that they did not know the name of the individual or anything about the injury or the follow up but would ask other staff.

Absence of active treatment for individuals not attending day program

- During a site visit to one of the residential units, an individual was observed in the unit with no staff interaction. One staff was engaged in a personal phone call on a cell phone talking about holiday plans and the other staff was watching TV while a second individual slept hunched over on her side in a chair.

- During a site visit in one of the residential units 6 staff were observed in the unit with 5 individuals. No active treatment or programming was occurring. Shortly after Investigation Unit staff arrived, Howe staff started to engage in some activities. One individual, who had a one to one staff assigned only to him, asked the assigned staff to go outside. In response staff said "No, I'm not going outside." No appropriate explanation was provided to the individual.

Failure to provide training to individuals regarding medications

- Howe staff advised an individual who was hospitalized that he was put on Depakote "for his cholesterol." When Investigation Unit staff told the individual that Depakote was not a cholesterol medication and suggested that he speak with his nurse for clarification of the purpose for his medications, the individual stated that staff do not listen when he makes such requests and have not provided him with any education about his medications.

**Death Investigations:**

An extraordinary level of callous disregard for the individuals living at Howe is plainly evident for a review of the records of the 3 deaths most recently reviewed by the Investigation Unit. As with the other 14 people who have died, the records document numerous lapses in

care similar to those that have been identified repeatedly by this and other investigative agencies. In looking at the months that preceded each death, the following serious lapses in care were noted:

**Death 1**

An individual died of metastatic adenocarcinoma. He had been residing at the Howe center since July of 1985. Prior to his death he developed decubitis ulcers to the lower area of his tail bone, had evidence of poor care related to basic hygiene, and staff repeatedly disregarded doctor's orders related to his care.

**Death 2**

In the six months that preceded the individual's death, records reveal months of substandard care by Howe staff. The individual was provided nourishment through a g-tube and had a suprapubic catheter that drained urine. Despite the presence of these two devices, through which nearly all fluids would pass, Howe staff routinely failed monitor intake and output totals as was ordered by the attending doctor. When Howe staff did attempt to monitor intake/output over a 9-day period, the individual purportedly took in approximately 11,000 cc's, or 23.25 pounds, more in fluids than he excreted. This however allegedly led to only a 0.6 weight gain.

In addition to Howe's failure to accurately measure fluids, Howe nursing staff were unable to follow such routine orders as monitoring vital signs, measuring blood sugar levels, and notifying the doctor of lab values as directed.

The individual also suffered from lumbar stenosis and degenerative joint disease of the spine and hip. Despite these conditions, Howe nursing staff did not conduct any routine pain assessments to determine the effectiveness of his prescribed pain relief medication. Additionally, no attention was given to the potential link between the individual's pain response and his documented uncooperativeness during routine procedures that were physically demanding for him such as being weighed.

In spite of orders for regular position changes and whirlpool baths to prevent the development of decubitus ulcers, staff failed to follow those orders and the individual developed ulcers before his death.

Several months prior to his death, the individual went on an outing with a family member. Upon his return, the family member informed staff that she noted a large flank bruise 10 cm X 8 cm in length. Both the size and area of the bruise are consistent with signs of abuse. Despite this, no investigation into the possibility of abuse was explored by Howe staff.

**Death 3**

The level of staff apathy to the care and well being of people living at Howe is best reflected in the care given to this individual on the day of his death. The record reveals that in the early morning staff noted that the individual was unresponsive and not breathing. Rather than provide CPR, as nursing staff are trained to do, the Howe nurse responded by placing a mask over the individual's mouth and pricking him with a pin. The individual's records also revealed that he had Hepatitis C. While physician orders required staff to check on the individual's well being every 30 minutes, hospital and paramedic records noted the presence of rigor mortis.

The records also reveal that the individual had a shunt placed in his brain to drain fluid. Such shunts require routine monitoring to ensure that they continue to function properly. In the spring of 2007 a CT scan of the head was performed. The doctor performing the scan recommended that the facility obtain prior CT scan results to compare the findings with the current result to determine if the shunt was continuing to function properly. Howe failed to provide this comparison.

The individual's records are also replete with numerous other examples of poor care including:

Failure to follow MD orders with respect to vital signs and monitoring
Failure to obtain consents for services provided and before use of sedation
Failure to monitor bowel habits appropriately
Failure to properly address weight issues
Falsification of monthly progress notes by Howe doctors.
Failure to provide adequate physical therapy as ordered

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As is plainly evident from each of our reports and the reports of other state and federal agencies, the same critical errors, lapses in care, failure to follow routine orders, woefully inadequate programming and services continues unabated at Howe. It is unconscionable that vulnerable people continue to be injured, suffer and die because the State chooses to maintain a dangerous institution which is irrefutably beyond repair and chooses to place special interests above the interests of the people the State is supposed to be serving. We again call upon the State to render a decision to close Howe and develop a reasonable transition plan which will provide a full array of meaningful choices for people with disabilities and their guardians as to where they will live.

Should you need any additional information from us regarding the information set forth above or if you or your staff have any questions, please do not hesitate to contact me at 312.895.7314.

Sincerely,

Zena Naiditch

ZN:dwt

CCs:

Carol L. Adams, Ph.D., Secretary
Illinois Department of Human Services

Grace Hou, Assistant Secretary
Illinois Department of Human Services

Lilia Teninty, Director
IDHS - Division of Developmental Disabilities

Inspector General William Davis
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Illinois Department of Healthcare and Family Services

Alice Holden
Centers for Medicare & Medicaid Services - Region V

May 19, 2008

Governor Rod R. Blagojevich
Office of the Governor
100 West Randolph Street, Suite 16-100
Chicago, Illinois 60601-3220

Dear Governor Blagojevich:

For nearly a year-and-a-half, this organization has reported the results of its ongoing investigation of numerous deaths and very serious longstanding problems at the Howe Developmental Center. In spite of detailed reports documenting extraordinary problems, no improvements at Howe have been noted and people continue to die.

The Abuse Investigation Unit has continued to conduct unannounced site visits to the Howe Developmental Center and has reviewed the records of three more individuals who have died, brining the known total to 20 individuals since September 2005. Had 20 individuals without disabilities died in a private hospital in this State, we have no doubt the State's response would be swift and aggressive.

During one of the recent site visits Investigation Unit staff also conducted a review of the charts of 3 individuals who reside in Unit 3, the Unit which Howe has touted as the most likely to be recertified by the Centers for Medicaid and Medicare Services. However, the same abysmal care so evident in the other units was plainly evident in Unit 3.

In a span of time covering less than 3 months, the Investigation Unit identified 10 categories of poor or dangerous care for the three individuals living in Unit 3 and again found evidence of falsified documentation. Significant findings include:

- **Orders for vital signs not being followed**
- **Orders for neurochecks following head injuries not being followed**
- **Restraint episodes without appropriate orders or follow up**
- **No notification of physician in response to elevated blood glucose levels**
- **No nursing documentation related to an identified instance of hypoglycemia**
- **No nursing assessments with respect to hypo or hyper glycemic blood levels**
- **Graph data purports to show improvement when chart documents problems**
- **Failure to provide services to meet individual needs**
- **Poor pain management**
- **Poor communication and follow up with psychiatrist**

**Chart One:**

Orders for vital signs and neurochecks not being followed

- The chart for an individual reflected various incidents of self-abusive and aggressive behavior. Although ordered to monitor vital signs following administration of anti-anxiety medication, staff failed to appropriately to do so. Following physician orders to conduct neurochecks to monitor for head injuries following episodes of self-abusive head banging, the staff failed to conduct the assessments.

Restraint episodes not documented and without physician orders:

- In a progress note staff indicated that due to aggressive behavior staff "had to put her in restraints every two hours". The chart contained no documentation related to the restraint episodes and no evidence of nursing progress notes or assessments of the individual while in restraints could be found.

**Chart Two:**

No notification of physician in response to elevated blood glucose levels

- Since December 26, 2007, staff have documented a consistent and worsening change in an individual's behavior with noted soiling (defecating and urinating) on herself where such incidents did not previously occur. Staff have also documented that individual was not taking fluids. In response to evidence of elevated blood sugar levels, a physician ordered staff to notify him if the individual's level exceeded 200. In December alone, staff failed to notify the physician of blood sugar levels, which reached as high at 310 on three occasions.

No nursing documentation or assessments related to an identified instance of hypoglycemia

- In January, a nurse documented that the individual had low blood sugar and ordered staff to give the individual breakfast. The nurse indicated that she would return to follow up and assess the individual's condition after breakfast. The chart contained no documentation of the blood level identified as low by the nurse and contained no evidence that the nurse ever returned to assess the individual's condition or conduct any follow up.

**Chart Three:**

Graph data purports to show improvement when chart documents problems due to the failure to meet individual needs

- An individual was transferred into unit 3, the unit self identified by Howe to be the unit that is providing the best services and closest to re-certification, yet in less than three months, the individual's behaviors substantially worsened and the "best unit at Howe" determined that they could no longer handle her and sent her back to her original house. Data graphs allegedly tracking target behaviors reveals a *decrease* in the individual's physical aggression and self-abusive behaviors since September 2007. The data identified only two incidents of physical aggression or self-injurious behaviors. This graph data is in stark contrast to data reflected in the progress notes in the individual's chart which indicate numerous incidents of maladaptive behavior of such severity that the individual was sent back to her original house. The facility's data collection process does not appear to be any reflection of the actual behaviors noted, which calls into question the reliability of any of the facility's data that indicates improvements in care have been achieved

Poor pain management

- Despite a physician's order to administer Tylenol during a 48-hour period if the individual had any complaints of pain, no pain medication was administered following the individual's complaints, which were documented by nursing staff.

Poor communication and follow up with psychiatrist

- A psychiatric assessment recommended that the current antipsychotic medication not be used and suggested that a new medication Invega would offer the individual substantial benefits. The chart documented that Invega is not available at Howe for reasons that are not clear. Staff did not follow up with the psychiatrist to solicit alternate recommendations for medication.

**Death Investigations:**

**Death One**

On November 27th, 2007, an individual died at a hospital shortly after her transfer from Howe. She was 38 years old. Howe doctors transferred the individual following notification on November 23rd, 2007 of severely elevated liver enzyme levels and a dangerously high potassium level. Our review of the care provided to the individual prior to her death reveals more of the same serious lapses in medical care and inattention to the well-being of the individuals living at the Howe that have been identified in scores of previous investigations.

The lab work performed revealed an on-going serious concern related to the function of the individual's liver. In response to these identified issues, Howe doctors scheduled consultation visits with a local hepatology clinic in an effort to determine the cause of her adverse lab results. On September 13th, 2007, slightly more than two months prior to her death, the hepatology clinic that had been seeing the individual indicated that they were unable to come to a definitive

conclusion as to the cause of the liver function abnormalities and ordered follow up within one month and stated that the individual would need serial imaging to properly evaluate the condition of her liver. The Howe physician did not review the report until mid-October and no follow up appointment was ever conducted.

The lab values reflective of liver function in September were as follows (normal values provided in parens):

| | | |
|---|---|---|
| AST | 143 | (10-42) |
| ALT | 181 | (10-50) |
| ALP | 311 | (40-125) |

By the time of the individual's transfer to the hospital shortly before her death in November the liver function results were as follows:

| | | |
|---|---|---|
| AST | 949 | |
| ALT | 1067 | |
| ALP | 949 | |
| Albumin | 3.1 | (3.4-5.0) |

Furthermore, documentation as early as November 7th, indicates awareness by Howe physicians of facial swelling. As facial swelling may be indicative of liver function problems and given the individual's known history of liver concerns, a prompt and thorough hepatic assessment should have been provided. Instead Howe physicians waited more than two weeks to order the appropriate lab tests.

In addition to the egregious inattention to a worsening medical condition, our review of the care provided revealed other on-going lapses in care including:

- Annual physical done in September of 2007 defers liver assessment to the hepatology clinic. Such deference is inexcusable in the absence of diligent and appropriate follow up with the clinic.

- Monitoring as ordered by a physician was neglected by Howe Nurses.

- In an effort to combat dehydration, Howe physicians gave clear orders with respect to hydration. While the chart contains documentation which purports to reflect that this hydration was given diligently by staff, medical evaluations demonstrate evidence of dehydration which suggests that staff falsified the chart.

**Death Two**

In January 2008 an individual died at Howe. Our review of the circumstances surrounding the death and of the care provided by the Howe SODC in the months prior to the death reveal the same on-going patterns of poor care that expose all individuals at Howe to undue risk.

Our review of the care given identified seven broad categories that reveal the type of systemic failures at Howe that jeopardize the health and safety of all individuals.

1. **Failure to identify an emergency situation/Failure to monitor appropriately.**

   The individual was noted to be unresponsive and bluish gray in color by Howe nursing staff during medication time. The Howe nurse called the individual to receive her medication. When she failed to respond, nursing staff approached her, noted her condition and appears to have appropriately responded to the emergency. Of concern, however, is the quality of direct care staff monitoring. At the time of her death, the individual was on visual observation status. Direct care staff failed to note that the individual had stopped breathing and was becoming blue in color despite the expectation that they were to diligently monitor her.

2. **Failure to follow physician's orders/Failure to adequately monitor adverse health condition.**

   In the months of October and November 2007 on at least three separate occasions, Howe physicians ordered Nursing staff to monitor the individual's health condition through measurement of vital signs or neurochecks every shift for 48 or 72 hours. These orders were not followed and the necessary assessments were not provided. On another occasion, Howe nursing staff merely initialed on the medication record that the vitals were taken but failed to document the results of these assessments in the record.

3. **Failure of nursing staff to appropriately monitor bowel functioning/Failure of Direct Care staff to appropriately notify nursing staff/Failure to appropriately respond to identified bowel monitoring concerns**

   In early November of 2007 a Howe physician ordered nursing staff to monitor the individual's bowel movement pattern. On two occasions in mid and late November the individual was noted not to have had a bowel movement on three and four consecutive days respectively. There was no identified documentation by Howe direct Care staff indicating nursing staff was informed. PRN medication was not provided following three days without a bowel movement as ordered. Nursing staff failed to diligently monitor bowel functioning despite the specific physician's order to do so just four days prior to the first incident.

4. **Failure of Howe medical and nursing staff to identify and respond to trends of data indicating potential adverse health conditions**

Howe staff documented a steady progression of weight loss that went unnoted by Howe physicians and nurses. The weights documented are as follows:

| | |
|---|---|
| August | 104.9 |
| September | 99.4 |
| October | 96.2 |
| November | 93.8 |
| December | Not taken |

Over the course of four months, the individual experienced greater than an 11 pound loss of weight. This information coupled with labs done in September of 2007 that revealed a low albumin level could indicate that the individual was not getting adequate nutrition.

5. **Failure of Direct Care staff to notify nursing staff of injuries/Failure of Howe nursing staff to appropriately monitor and assess injuries**

In November of 2007 direct care staff documented that the individual hit her face against the corner of the wall. The note states that nursing and administration staff were notified, but the record did not reveal any follow up documentation by nursing or administrative staff.

In January of 2008 direct care staff documented that the individual was hitting her head against the wall. Direct care determined that there were no injuries despite the lack of training in assessing health conditions and neither nursing nor administrative staff were notified.

In October of 2007 direct care staff noted bruising to the left top side of the individual's buttocks. While nursing and administrative staff were notified, the record revealed no assessments of the injury.

The available record contained no injury reports for the incidents documented in the progress notes.

6. **Failure of nursing staff to appropriately assess and address pain**

In October of 2007 direct care staff documented that the individual was irritable and suspected that she was experiencing pain. Nursing staff were notified, but the record did not reveal any pain assessment conducted by nursing staff nor were pain medications provided.

7. **Failure to provide necessary psychiatric assessments**

Over the course of the last 3 months of the individual's life, the record reveals ample documentation regarding worsening behaviors. Documentation reveals an increasing pattern of screaming and self-injurious behaviors. Despite this noted pattern, Howe failed to provide necessary psychiatric assessments. The last psychiatric evaluation that was available in the record was conducted in May of 2004.

**Death Three**

In February 2008 an individual died at Howe. Our review of the death reveals serious problems in the care provided by Howe staff with respect to identification of risk, nursing and medical assessments, continuity of care and appropriate emergency response that evinces a system of care at the Howe center that jeopardizes the health and safety of everyone at the facility.

The deficiencies noted that may have directly resulted in the individual's death include:

1. **Failure to properly identify risk**

Prior to August of 2006, the individual's diet order was mechanical soft with soft cooked meats, no ground beef. A swallow study conducted at that time determined that the mechanical soft diet was no longer necessary and suggested a return to a general diet. A follow up assessment approximately 3 months later found that the individual was tolerating the change and found that no further assessment was necessary for five years *unless medications are changed that may effect eating/swallowing.*

In December of 2007, the individual's medication regimen was changed to include an anti-psychotic medication called Seroquel. In 2005 the FDA issued an alert on the use of Seroquel that identified difficulty swallowing as a "serious side effect" of the medication.

Despite the individual's history of difficulty swallowing and despite the known risk related to swallowing associated with the use of Seroquel, Howe physicians failed to provide a follow up swallow assessment. Less than three months following the initiation of Seroquel, the individual died from choking.

2. **Failure to provide competent emergency care**

A). **Howe administrators failed to properly train staff in use of the emergency phone system**

In February of 2008 the individual was eating dinner when he began to choke. Staff in attendance attempted to activate the emergency phone system but found that there was no dial tone. Howe administration stated that the system was working properly but that there is a few seconds delay before a ring tone is heard.

Howe administration further stated that the direct care staff panicked when a dial tone was not immediately heard and promptly sought nursing staff. Staff that had been properly trained in the use of the emergency system would have been made aware of this delay.

**B). Howe staff failed to properly identify the nature of the emergency**

Documentation maintained by the nurse responding to the code states that the Direct Care staff "*walked over to the nursing station*"...*and told a nurse that the individual ... is not looking right*". Such response hardly appears to be actions taken in an emergency and fails to properly convey the gravity of the situation. It also does not appear that Direct care staff "panicked" as a person who properly identifies an emergency situation would not *walk* to obtain help. Furthermore, the investigation conducted by the Office of the Inspector General found that the initial choking incident occurred at 5:20 p.m. Emergency care was not provided by the RN until 5:25. It took staff 5 minutes to respond to an emergency.

**C). Howe Nursing staff failed to properly administer CPR**

The investigation conducted by the Office of the Inspector General revealed that the RN responding to the code stated that the individual's chest was rising and falling with rescue breaths while CPR was being administered. When the paramedics responded, however, they found that the individual's airway was blocked by a bolus of food. The paramedics removed the obstruction and provided proper emergency intervention. The rise and falls staff alleged was observed were likely due to air delivered to the stomach due to improper head tilt during CPR. Staff properly trained in CPR should be able to identify situations in which airway exchange is not occurring.

**D). Howe Medical staff failed to identify the improper administration of CPR.**

The emergency care provided reflects the fact that the Physicians at Howe are no more equipped to provide competent emergency care than are nursing and direct care staff. The Howe physician who responded to the emergency documented that he observed "CPR being administered very appropriately". A physician should have been able to identify an improper extension of the head and would have realized that air exchange was not occurring. Additionally, the physician should have assessed the lungs for evidence of air exchange.

**3. Failure to follow physician's orders/Failure to adequately monitor adverse health condition.**

On at least four occasions in just the last two months of the individual's life, Howe physicians ordered Nursing staff to monitor his condition through measurement of vital

signs every shift for 72 hours. The record revealed that these orders were not followed and the necessary assessments were not provided.

4. **Failure to maintain records in a manner that clearly communicates care provided**

Our review of the record revealed a system of documentation at Howe in which care that is provided is documented in an inconsistent and haphazard manner. Routinely upon our reviews of this and other files, chart documents are missing, data is recorded in different areas of the chart depending on the preference of the staff, and the record provided requires hours of review before a reflection of the care given can be gleaned. Such poor record keeping not only causes difficulty in assessing the quality of care provided, it usurps the purpose of maintaining records which is to facilitate the exchange of information among all levels of care providers for the benefit of the persons served. Records maintained in the manner that Howe maintains records precludes any meaningful use of the information gathered and is a reflection of the value placed on quality care at the institution.

Given the extraordinary number of people who have died, the manner of their deaths and the truly abhorrent "care" provided at Howe, we must ask just how many people this State will let suffer and die before the State will be willing to take the necessary steps to close a facility that is both dangerous and so fundamentally flawed that it is simply irreparable. It is unconscionable that, given the millions of dollars infused into Howe to improve the standard of care, which clearly have been wasted, the State continues to demonstrate such callous disregard for the lives of the people living at Howe. We call upon the state to take immediate action to begin the closure of the Howe Developmental Center.

Should you need any additional information from us regarding the information set forth above or if you or your staff have any questions, please do not hesitate to contact me at 312.895.7314.

Sincerely,

Zena Naiditch

ZN:dwt

CCs:

Carol L. Adams, Ph.D., Secretary
Illinois Department of Human Services

Grace Hou, Assistant Secretary
Illinois Department of Human Services

Lilia Teninty, Director
IDHS - Division of Developmental Disabilities

Inspector General William Davis
Illinois Department of Human Services

Damon Arnold, M.D., M.P.H., Director
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Enrique J. Unanue
Deputy Director - Office of Health Care Regulation
Illinois Department of Public Health

Patsy Swan
Developmental Disabilities Section
Illinois Department of Public Health

Director Barry Maram
Illinois Department of Healthcare and Family Services

Alice Holden
Centers for Medicare & Medicaid Services - Region V

December 16, 2008

Commission on Government Forecasting and Accountability
703 Stratton Office Building
Springfield, Illinois 62706

Subject: Testimony of the Illinois Hospital Association Regarding the Proposed Restructuring of the Tinley Park Mental Health Center

Dear Madams and Sirs:

The Illinois Hospital Association represents approximately 200 hospitals and health systems in the State of Illinois. As community resources for persons with a variety of heath care needs, including those associated with mental illnesses and substance use disorders, we recognize the importance of ensuring access to adequate and appropriate mental health acute care, in every community of our state. We, therefore, wish to take this opportunity to comment about the proposed restructuring of the Tinley Park Mental Health Center (TPMHC), which you considered in a recent hearing on December 11, 2008, in Tinley Park, Illinois. In this hearing, you also considered the closing of the Howe Developmental Center. Our comments are limited only to issues related to Tinley Park Mental Health Center (TPMHC).

We note the Illinois Department of Human Services, Division of Mental Health (DMH) has not proposed the closure of Tinley Park Mental Health Center, but, rather, its replacement by a new building and management. We would support the replacement of the old structure with a new facility if it satisfies the following criteria: access to inpatient acute psychiatric services remain available to persons with mental illness under the same or similar terms and circumstances as are currently available; during the transition from the old to a new facility, access to inpatient services are maintained at the same level as are currently available at TPMHC; there is no overall loss in inpatient capacity in state-operated hospitals. Although we would have several questions about the proposed new facility, we recognize they would be premature. Moreover, these operational questions are secondary to the fundamental question: How will the state ensure persons with mental illness have access to acute care inpatient care that is appropriate for a given patient's clinical condition through its existing or future structures?

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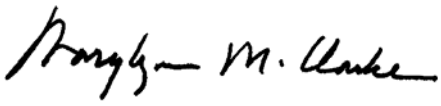
Illinois has closed and reduced in capacity many state-operated hospitals over the past decade. Unfortunately, the resources dedicated to these facilities have not shifted to the community, either to private hospitals with psychiatric services or to community mental health centers. As a consequence, many persons with serious mental illnesses are going without care or are obtaining it when they are in a crisis. A recent IHA survey of hospital emergency departments attests to a growing number of persons with mental illness seeking care in the ED. We estimate as many as 300,000 persons with mental illness were treated in our EDs in 2007. And, when there, persons with mental illness wait hours for an inpatient bed—primarily because there are not enough inpatient psychiatric beds to meet demand. National data demonstrate similar trends.

We believe that any restructuring or closure of a state-funded facility must be made according to principles and a plan that assures those for whom the state has served as a safety net remains protected. Our Behavioral Health Steering Committee, a statewide, interdisciplinary group of mental health and substance abuse care experts, developed a set of principles and recommendations for the restructuring of the Tinley Park Mental Health Center in 2004. These principles and recommendations remain relevant today and offer guidance for a restructuring of a state-operated hospital. They are attached.

Thank you for the opportunity to present these comments.

Respectfully,



MaryLynn M. Clarke
Senior Director
Behavioral Health Constituency Section

Attachment

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**Position of the Illinois Hospital Association Behavioral Health Steering Committee Regarding the Closure or Other Restructuring of the Tinley Park Mental Health Center Facility**

Based on principles adopted in 1997 by the IHA Behavioral Health Steering Committee (Steering Committee) and Board regarding the privatization of state-operated mental health facilities (SOF), the Steering Committee on February 22, 2005 identified the following issues as relevant to the decisions related to whether or how the Tinley Park Mental Health Center facility should be restructured. It was their recommendation that these issues must be addressed to ensure access to an appropriate level of care for persons with mental illness:

- **The State must clearly state its vision regarding mental health services for Illinois citizens and define, publicly, its intent with regard to the role and relationship of its facilities and community resources.** The failure to define the role of the SOF in terms of its mission for the citizens of the State and relationship to community hospitals and other community providers strains the relationship between the parties, interjects ambiguity where there should be clarity, and, more importantly, does not put patients, families, and all Illinois citizens first.

- **Articulate criteria regarding which patients are most appropriate for a private hospital and which are most appropriate for a SOF.** Currently, admission and length of stay criteria are lacking or poorly defined. Admission criteria primarily are about the patient's funding source: If you are a Medicaid patient, you go to a private hospital. If you are uninsured, the SOF may accept you.
  - Clinical criteria are needed to determine before an admission whether the patient would be better served in the SOF or private hospital. Criteria are also needed to determine when a transfer is appropriate and necessary.
  - Criteria are also needed about medical services the DHS views as medically necessary and, therefore, eligible for payment.

  We believe that the SOF is appropriate for patients who are not successfully treated in community hospitals. These patients often exhibit the following characteristics: they are treatment resistant and/or have had multiple (three or more) admissions in the previous twelve months, and/or may require a longer length of stay (beyond 10 days). And, they may be unmanageably violent.
  Private hospitals are appropriate for patients who present medical complexities that benefit from access to multiple specialties; patients who need to be stabilized and treated within the shortest time frame; and patients who will benefit from the diagnostic and other therapeutic resources of an acute care setting.

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Patients with co-occurring disorders are caught between narrowly construed regulatory and public financing schemes that do not support access to appropriate services. For example, the state SOFs reluctantly accept patients with a primary diagnosis of substance abuse; Medicaid does not reimburse a private hospital for substance abuse treatment or rehabilitation, but only detoxification services, leaving the addicted person no access to treatment for their addiction in an acute care setting. The Illinois Department of Alcoholism and Substance Abuse licenses and pays for "sub-acute" Medicaid services, not acute services such as those needed by a substance abuse patient who has attempted suicide or has a psychiatric condition. Thus, the State financing of behavioral services lacks a comprehensive and coordinated rehabilitative focus, and thus leaves gaps that perpetuate expensive relapse and readmission.

Patients with developmental disabilities with mental illness also have few options for acute treatment available to them today. Given that the private sector cannot generally treat these individuals on an acute basis, they pose a natural population of citizens for which the State should assume responsibility. At a minimum, the State must fund, either directly or by arrangement, services that effectively meet the complex needs of these individuals.

- **Ensure patients in the private sector have community access to the same resources as are afforded patients in the SOF.** A patient upon discharge from a SOF has a firm referral to a community mental health provider. The patient being discharged from a private hospital must also have the same assurance he or she will have an appointment within the time frame dictated by his or her condition. Access to medication must also be assured, since failure to adhere to medication regimens often leads to readmission to an acute care setting.

- **Improve Medicaid rates.** Medicaid rates for inpatient psychiatric services are inadequate and vary across the state. The most vulnerable providers often have the lowest rates. Inadequate Medicaid rates coupled with burdensome administrative processes further weaken a fragile private inpatient psychiatric community. Because a large number of SOF patients are presumed to be Medicaid eligible, the adequacy of Medicaid payment is an essential variable in the shift of the locus of care to the private sector. If the private sector is not financially viable, patients will be at risk of having no options should the SOF also be unavailable. Moreover, the mechanisms under which the hospital either obtains DHS or Medicaid payment must also support rather than burden the provider. For example, the Community Hospital Inpatient Psychiatric Services (CHIPS) contract, which is the mechanism through which DHS contracts with private hospitals to serve a patient who otherwise may be treated in a SOF, requires a hospital to always attempt to qualify a patient for Medicaid before DHS pays the hospital. This is a costly and burdensome process, causing significant payment delays. For hospitals with low Medicaid rates, they will receive less money than they would have

received from DHS, following a cumbersome administrative process, and following a lengthy period of time. Few, if any, hospitals can knowingly adopt a business model that requires them to seek out less reimbursement for services first.

Therefore, in order to ensure the private sector is able to care for the patient with mental illness:

- Medicaid rates for inpatient hospital psychiatric services must be improved. The State should at a minimum be willing to pay the private hospital with which it contracts the same per diem as it paid itself under Medicaid.
- Medicaid rates should never be less than the rate DHS pays. Ideally, both rates should be comparable and adequate to cover reasonable costs.
- The burdens associated with completing MANG applications should be shared by the State. For example, the State should provide staff support to the hospital that must complete lengthy applications. Moreover, the hospital should not be penalized if a physician does not believe a patient is disabled.

- **Make the courts more user-friendly and accessible to the private sector.** Many patients who refuse medication or admission require involvement with the judicial system. Courts are not easily accessible; there are numerous continuances; psychiatrists and staff must accompany the patient to court. There is no compensation for this. The courts must be more patient and user friendly to support the needs of patients, families and providers in the communities who must negotiate with this system. Necessary legal hearings could be conducted more creatively and efficiently. For example, a hearing could be held at the hospital, when feasible, or through the use of tele-technology that is transmitted from the courthouse or another central location. This would also assist in obtaining the support of psychiatrists to testify in such hearings.

- **Maintain in the community the funds currently allocated to the state-operated facilities.** Closure of the SOF should not reduce the overall financial support available for mental health services, i.e., there should not be a net loss of funding to the community. There is evidence that fewer funds will be available to the community, including hospitals and community mental health centers, than are currently allocated to Tinley Park SOF.
  The closure of other SOFs has resulted in a net loss to the community of mental health funding. If the community alternatives to the SOF are not strong and well financed, patients will need the safety net provided by the SOF. Moreover, the DHS fee-for-service conversion threatens the financial viability of community mental health centers. The system is being tugged at both ends of the continuum. At a minimum, the funds currently allocated to the Tinley Park SOF should continue to be available either for its operations or for a combination of state operated, private operated acute services, and community outpatient services.

- **Formally evaluate effects of reducing or eliminating SOF capacity against program goals.** Perform a formal evaluation of any program of SOF reduction or deinstitutionalization to determine whether the program's goals are truly being met, the effect of the program on all of the parties involved (community hospitals, community behavioral health providers, consumers, and Illinois citizens). Make this evaluation public and available for comment.

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December 11, 2008

Commission on Government
Forecasting and Accountability

RE: Howe and Tinley Park Closures

Dear Commission members;

The Illinois Nurses Association wishes to express its concern regarding the handling of the Howe and Tinley Park facilities. First and foremost, we firmly believe that the state must develop a plan for adequate funding to guarantee a sufficient level of acute care mental health services to remain available in this area of the state. Funding must be made a priority to meet the needs of the people who reside at Howe and their families throughout the transition process. We also believe that if any gain is realized from these closures, that those funds, should remain in the Illinois mental health system.

The second part of our concern is in relation to the nurses employed at these facilities. We would be remiss if we did not address our concern for these individuals. The Illinois Nurses Association has worked hand in hand with several agencies to help minimize the impact of the nursing shortage for the public of Illinois. With that in mind, INA emphatically believes that all nursing vacancies at these two facilities must be filled expeditiously to guarantee a safe quality of care continuum for the residents. Due to the state's failure to meet the staffing needs of those cared for in the state system, we firmly believe that Howe and Tinley Park are not the only facilities within the system who are failing to meet the most basic standards of care needs. Currently there is a mandatory overtime crisis for nurses working in state facilities. This only serves to put the public of Illinois at risk. An agreement exists between INA and the state to expeditiously fill these vacancies. The state must abide by and enforce this legally binding agreement.

Respectfully,

Pam Robbins RN, BSN
President, Illinois Nurses Association

WILL COUNTY HEALTH DEPARTMENT
&
COMMUNITY HEALTH CENTER

# State of Illinois
# Commission on Government Forecasting and Accountability
# Hearings Regarding the Closure of Howe Developmental Center and Tinley Park Mental Health Center

## December 11, 2008

The Will County Health Department's Division of Behavioral Health Programs advocates for the following:

1. We recommend that the Tinley Park Mental Health Center (TPMHC) would only be closed once the one hundred (100) bed replacement hospital is fully functional and operational.

2. That the State of Illinois – Department of Human Services(DHS), Division of Mental Health (DMH) reconsider the privatization of the replacement facility and instead continue to maintain it as a state operated facility (SOF).

3. That the State of Illinois – Department of Human Services, Division of Mental Health consider relocating the new hospital to the Will County Area. Will county is one of the fastest growing counties in the United States. Its population is at 657,475 as of 2007. Joliet is the 4th largest city in Illinois, and nationally the 12th fastest growing city. There are also, as of October 2008, an estimated 82,311 uninsured residents in Will County. The Will County poverty rate rose from 5.1 percent in 2005 to 5.8 percent in 2006, according to U.S. Census data. That statistic means 38,694 people in Will County are living in poverty. These statistics will increase as the current economic crisis continues to unfold.

Joseph E. Troiani, Ph.D., CADC
Director of Behavioral Health Programs

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CGFA Meeting
December 11, 2008
RE: Proposed closure – Howe Developmental Center,
Tinley Park Mental Health Center

Senator Jeffrey M. Schoenberg
Co-Chairman

Representative Richard P. Myers
Co-Chairman

As President and CEO of Grand Prairie Services, I want to thank you for the opportunity to provide this written testimony to CGFA as you consider the proposal developed by the Department of Human Services, Division of Mental Health regarding the future status of the Tinley Park Mental Health Center.

Grand Prairie Services is the primary provider of safety net behavioral healthcare services in the four townships of Bloom, Bremen, Rich and Thornton within south suburban Cook County. For over 58 years we have provided community based behavioral health services delivered through a variety of contracts with the State of Illinois Department of Human Services, Divisions of Mental Health, Developmental Disabilities, Alcohol and Substance Abuse and the Department of Children and Family Services.

When the initial idea of closing/rebuilding Tinley Park Mental Health Center was presented in 2004/05, Grand Prairie Services was the lead south suburban agency in a workgroup created by the Department to develop a comprehensive community reinvestment plan in response to the potential closure. During that process, Grand Prairie Services put forth an enormous amount of time and energy in coordinating meetings with community based stakeholders including Mental Health and Substance Abuse providers, hospitals, and the National Alliance of Mentally Ill - South Suburbs of Chicago to develop the reinvestment plan. The proposal was designed to include the much needed expansion of community based behavioral healthcare services, development of a psychiatric triage service for our south suburban communities, and a comprehensive response to developing services in a region that has historically been underserved.

At a recent press conference, the Division of Mental Health proposed the temporary consolidation of mental health services to a single site location on the campus of Tinley Park Mental Health Center, with the ultimate goal of building a new state of the art inpatient psychiatric hospital.

As the Commission considers the DMH proposal, we respectfully request that the ultimate recommendation of the Commission include a mandate that the Division of Mental Health consider the following tenants:

- Within the scope of the project, consideration should be given to the previous reinvestment proposals developed by community providers. The comprehensive plan should not only include the construction of a new inpatient hospital, but should also include the much needed expansion of community based services within the communities served by the new inpatient facility.
- Expanding on the above comment, consumers and community stakeholders must be included in development of any proposal for a new hospital and community service expansion.
- If a new inpatient hospital is constructed, its location must provide easy access for consumers and their families and be located in the south suburban areas of Bloom, Bremen, Rich or Thornton Township. Site selection of a new inpatient facility must be directly linked to the demographic profile of the consumers most likely to utilize the inpatient psychiatric hospital and not solely based on population and regional growth.
- The development of a new inpatient hospital location must include the availability of Child & Adolescent Inpatient Services for the south suburban area. The south suburban area, specifically, is in desperate need of local inpatient services for children and adolescents.

As an organization, Grand Prairie Services is a primary advocate for the continued and ongoing development of quality behavioral healthcare services as part of the safety net continuum for individuals without insurance, Medicaid and/or Medicare. We are also staunch advocates for services that best meet the needs of the community and understand that those services must be a quality continuum starting with comprehensive crisis service availability, inpatient care and comprehensive outpatient and supportive services.

Once again, we appreciate the opportunity to share our thoughts regarding the Tinley Park Mental Health Center proposal and would be available to answer questions or provide additional information you may need as a Commission to make your recommendation. I can be reached at 708-444-1012, ext. 1501. Thank you.

Sincerely,

Dennis Regnier
President and Chief Executive Officer

CC: CGFA Members
Dan R. Long, Executive Director, CGFA

MHAI
Mental Health America
of Illinois

# Comments of Mental Health America of Illinois on the Proposal to Close Tinley Park Mental Health Center

**Presented to the**

## Commission on Government Forecasting and Accountability

**December 11, 2009**

### Introduction

Mental Health America of Illinois (MHAI) is the oldest state-wide mental health advocacy organization in Illinois. Founded by Jane Addams, we will be celebrating our centennial in 2009. MHAI applauds the vision and leadership which Director Lorrie Rickman-Jones has shown in proposing a new inpatient mental health facility for the region served by Tinley Park Mental Health Center. The current facility is old, inappropriate and inadequate. A new facility is needed. However, the documents which have been presented to this Commission and shared with the public thus far, raise serious concerns which are directly relevant to the requirements imposed by the State Facilities Closure Act, 30 ILCS 608/5-1, *et seq,* and may endanger the health and well being of persons with mental illnesses, their family members and the communities served directly and indirectly by Tinley Park. Most particularly, we are concerned that the existing physical facilities may be closed and dismantled and the land beneath them sold before we can be reasonably assured that an adequate replacement facility will be built. Thus, we urge the Commission to recommend that the existing facilities not be closed until we have a comprehensive plan for the new facility.

### Background

Since his election, Governor Blagojevich has pursued the closing of Tinley Park. This culminated in a formal proposal several years ago. At that time, Tinley Park had 140 beds. Encouraged by the Illinois legislature and many stakeholders and under the leadership of Director Jones, the Division of Mental Health created an inclusive and thoughtful process to review *how* Tinley Park could be closed without harming persons with mental illnesses and their families and communities and Tinley Park employees. This process resulted in the attached document entitled "A Vision for Mental Health Services in the Metro South Region" (May 5, 2005). MHAI strongly supported that vision statement when it was issued and continues to believe that it should be the template for any effort to close Tinley Park. We are concerned that some of the documents presented to this Commission, suggested that we have abandoned that vision.



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**The Need for Inpatient Beds**

The closure of Tinley Park must be viewed in the context of the history of state hospital closures in Illinois and other serious gaps in services. In 1950, Illinois had 55,000 state psychiatric hospital beds. Now we have only 1400, even though the state's population has doubled since 1950. These closure have also been accompanied by a substantial and continuing reduction in the number of private hospital beds. The main reasons for these closures is that the state has failed to adequately reimburse private hospitals for the cost of inpatient psychiatric care for the indigent.

Tinley Park is one of three state-operated facilities in the Chicago area. This fact enables the Department to shift admissions and patients between these facilities when the need arises. Indeed, admissions to all three facilities are now controlled through staff located at Madden Mental Health Center in Maywood. Unfortunately, the need for inpatient care in the entire Chicago area greatly exceeds the supply. Thus, it is not uncommon for the Department to advise emergency departments and community providers not to send seriously mentally ill persons to **any** of the three hospitals. The lack of state hospital capacity in the greater Chicago area has at times caused persons with serious mental illnesses to wait for many hours, strapped down inside ambulances, waiting in line at Madden. The Department's response to this inhumane situation was to require emergency departments to make reservations before sending someone to a state hospital. Unfortunately, it is easier to make a reservation at a trendy restaurant than to make one in a state hospital. As a result, persons with serious mental illnesses now wait for hours in emergency departments. MHAI knows of at least one person who waited many hours in an emergency department, finally gave up and walked away. He was found frozen to death in a dumpster a few days later.

The need for beds in the Chicago area is likely to be exacerbated by the Department's recent decision to downsize its only maximum security facility, Chester Mental Health Center. Persons from all over the state whose behavior requires a more secure setting are sent to Chester. The number of persons at all three Chicago hospitals who can be sent to Chester will be reduced, placing a greater burden on these facilities.

The Department has not done a needs assessment either for the area served by Tinley Park or the greater Chicago region. The Department did conduct a bed utilization study several years ago. However, utilization does not reflect need. Because we make it so difficult to obtain inpatient and outpatient psychiatric care, many people needing care end up in homeless shelters, nursing homes and in the criminal justice system. For example, the Cook County Jail is now the largest mental hospital in the state and there are more persons with serious mental illness in the state prison system (6,000) than in all of the public and private psychiatric hospitals in Illinois combined (5400). There are also more than 10,000 persons with mental illnesses in nursing homes. A true needs assessment would include all of these populations who could be served more appropriately in a hospital.

The Department appears to base its interim plan of having only 80 beds at the Maple unit on the

recent patient census data at Tinley Park. However, those numbers have been reduced by a deliberate decision by the Department to restrict admissions in the wake of an elopement/suicide almost two years ago. Prior to that tragedy, the census was at one hundred. There is no explanation in the Department's proposal for how it will handle the demand in excess of the eighty-bed capacity at Maple. Currently, those people are simply being denied appropriate treatment.

Nor does the Department's plan reflect the enactment of Public Act 95-0602 which took effect on June 1, 2008. This law, approved with overwhelming support in both the House and the Senate, dramatically lowered the standard for involuntary commitment. Passage of this law was based upon the legislature's view that people desperately needing inpatient treatment were not getting that treatment. Implementation of this law will either require substantial new inpatient capacity or dramatically increased funding for the community services which would prevent persons from deteriorating to the point where inpatient commitment is needed.

**The Availability of Alternative Services**

To be clear, MHAI does not believe that the best road forward is to increase the number of public or private inpatient beds. However, as we have reduced the number of inpatient beds, we have failed to adequately fund our community mental health system. That is why we are ranked no better than 35th in per capita spending on mental health services. Additionally, two years ago Illinois received an "F" from the National Alliance on Mental Illness, primarily because of our severely underfunded community mental health system. Since that failing grade, things have gotten worse. The state has reduced the availability of precisely those types of services needed to keep people with the most serious mental illnesses out of state and private hospitals. For example, due to inadequate rates, the number of providers willing to offer Assertive Community Treatment (ACT) had been reduced by more than half. This treatment modality has been proven to be among the most effective at preventing the deterioration which leads to preventable hospitalizations. Community providers have recently been told that additional cuts to their services are pending. Payment delays are threatening to put some of them out of business.

**Past History of Closures**

Illinois has moved from 55,000 state hospital beds to 1400 by closing and downsizing its hospitals. Unfortunately, we have never kept all of the money saved by these closures in the mental health system. Additionally, Illinois has a history of broken promises. For example, when Zeller Mental Health Center in Peoria was closed several years ago, the Department gave money to a private hospital to renovate an existing space to be used as a new inpatient facility to replace some of the capacity at Zeller. Despite having spent our tax dollars on this renovation, the Department then decided that it would not fund the operation of this new unit. Some people with serious mental illnesses in the Peoria area are being shipped to Singer Mental Health Center in Rockford (138 miles) or the McFarland Mental Health Center in Springfield. (72 miles). Based upon this history, MHAI is concerned that the services offered at Maple after July, 2009 will be inadequate and that, because of the state's budget crisis, no new hospital will ever be built

**The State's Plan**

The State's plan is to close all of the existing Tinley Park buildings, except Maple, by July, 2009. All of the mental health functions which will continue after July will be provided in the Maple building. The state will then contract with a provide vendor to build a new hospital somewhere in the Southland area, which will opened at an uncertain date in the future. The Department plans to operate eighty (80) beds in the Maple Building and one hundred (100) beds in the building to be constructed. The Plan is missing several key elements:

- A plan for the involvement of consumers and advocates in the planning for the new hospital
- An assessment of the treatment needs of Southland region and the Chicago metropolitan area
- A plan for providing services for those people who cannot be served at Maple since its capacity will be substantially less than the need
- An explanation of how those persons needing court-ordered involuntary commitment or involuntary medication will be served.
- Whether and how the pharmacy unit at Tinley Park will be replaced.
- A careful study of whether the privatization aspect of the plan will reduce the quality or quantity of services due to the need of the private provider to make a reasonable return on its investment.

**MHAI's Proposal**

We urge this Commission to adopt the following recommendation:

1. Support closing Tinley Park and replacing it with a new facility in the Southland region
2. Delay the closing and destruction of the existing Tinley Park buildings and the sale of the land until:
    a. a needs assessment is done for the Southland region and the entire Chicago area;
    b. a detailed plan can be created with appropriate input from consumers and advocates
    c. a contract has been signed (or other steps taken) guaranteeing the construction and operation of a new facility.

Mark J. Heyrman, Chair
Public Policy Committee
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# A VISION FOR MENTAL HEALTH SERVICES IN THE METRO SOUTH REGION METRO SOUTH MENTAL HEALTH PLANNING TASK FORCE

**May 5, 2005**

**Convened by Dr. Carol Adams, Secretary, Illinois Department of Human Service**

## Introduction

In September 2004, the Illinois Department of Human Services (IDHS), under the direction of Secretary Carol Adams, convened a special planning task force in the Metro South Region of Chicago to discuss and come to consensus around a renewed vision for mental health services in the area currently served by the Tinley Park Mental Health Center (TPMHC). The charge was that mental health services should be re-designed such that the region would provide future consumers with the best that the discipline has to offer-- drawing from best practices in use locally and nationally. The Secretary called for a bold vision.

While this planning process has been prompted by the State's budget crisis and discussions that have included a proposal to close TPMHC, the Secretary has advised the Metro South Mental Health Task Force (Task Force) that it should research and recommend alternate solutions that may include a public hospital option as well as other innovations. This plan represents the best efforts of the Task Force to think creatively and long term about optimal mental health services for the region.

## Vision Statement

We envision mental health services in the Metro South Region that fosters a future when everyone with a mental illness will recover, a future when mental illness can be prevented, treated or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatments and supports-essential for living, working, learning and participating fully in the community. [1]

Locally, we envision a system of care that is adequately funded, consumer and family driven, and geographically accessible. This system should continue to include state operated psychiatric beds seamlessly linked with community-based mental health services including the full spectrum of available in-patient and out-patient services. These mental health services will be guided by evidence based research and practice. Services will be linked to other community resources critical to stabilization and recovery, including but not limited to primary health care, affordable housing and employment services.

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[1] Adapted from the New Freedom Commission on Mental Health, Achieving the Promise: Transforming Mental Health Care in American. Final Report. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003. www.Mentalhealthcommission.gov. For free copies call 1-800-789-2647.

## Goals

To achieve this vision in our region we will strive towards achievement of these goals:

1. **Achieve adequate funding for mental health service enhancement and expansion in the Metro South region.**

Context: Historically, mental health services in the Metro South region have not been fully funded; and thus, gaps in services exist. If the service delivery system is to be reconfigured in any way, it is essential that no funds be lost to the region and that reimbursement levels be raised to cover the real costs of ensuring the highest quality mental health services to consumers.

   a. Achieve adequate funding levels for all needed mental health services in the region.

   b. Explore ways to increase funding for mental health services through increased federal match.

   c. Ensure adequate reimbursement rates for community mental health services and private hospitals for services such as: in-patient care, mental health court costs, post-discharge medications; substance abuse services etc.

   d. Funds resulting from the full or partial sale of TPMHC lands should remain in the Metro South region to support short-term and long-term infrastructure and service needs as determined by this plan. There should be no net loss to the region in dollars or services.

   e. Determine and maintain a reasonable number of state operated beds located in the region.

   f. Identify gaps in community based services and ensure funding for those services.

2. **Make prevention and consumer education central to a realigned mental health system in the Metro South region.**

   Context: Current evidence based research supports a best practice model that includes active consumer education as critical to prevention of mental illness and essential to stabilization and recovery.

   a. Build strong communities that foster "collective efficacy" or the notion that strong formal and informal social networks and controls make for healthier communities.

   b. Ensure strong linkages among the array of health and human service providers, law enforcement, housing and employment resources and services.

   c. Facilitate access to affordable primary health care, affordable housing and employment that pays a living wage.

   d. Provide consumers and their families with high quality information about their treatment options and about the full constellation of community resources available to assist them in stabilization and recovery.

3. **Foster inpatient care that is consumer focused and community based while building on the strengths of a public hospital system of care.**

   Context: Historically, TPMHC has been a critical anchor in the region. While providers and consumers value community based approaches to mental health, they also recognize that there is merit in having a public hospital in the mix to serve those who have exhausted their private insurance or who are uninsured. Such a hospital is also critical in serving severely mentally ill consumers who are a threat to themselves or others or who may be brought to the facility in lieu of criminal prosecution. At times, a public hospital is the most appropriate resource for the most seriously mentally ill. Once lost, it may never be replaced. While the short-term gains associated with the sale and closing of the state hospital may be attractive, they represent a one time revenue source, at a time when IDHS is being asked to expand services without continuing appropriations.

   a. Maintain a public hospital presence in the region, highly targeted to consumer needs as necessitated by behavioral management issues or functional impairment that may not be met by private hospitals such as:

      - longer term care and rehabilitation;
      - special services for mentally ill substance abusers (MISA);
      - special services for those with a dual diagnoses of mental illness and developmental disability;
      - special services for consumers who need court ordered treatment;
      - special services for consumers diverted by law enforcement from criminal to mental health services.

   b. Future planning for mental health services in Metro South should be based on a thorough study of the availability of private psychiatric beds and expected consumer demand over time. Public solutions should be innovative, fully funded, and in place *before* any closure or downsizing of TPMHC.

   c. Differentiate the roles of the state operated hospital and private hospitals by clearly defining roles and responsibilities, core services, definitions of acute and chronic care, and criteria for admissions and deflections to public and private hospitals.

   d. Requirements that ensure that consumers discharged from private hospitals are successfully connected with community based treatment options similar to those currently provided by state hospitals.

   e. Explore alternative public/private service and financing models that leverage the strengths of the public system and those of private system.

   f. Strengthen collaborative partnerships among all providers in the region's mental health continuum of care.

4. **Enhance and expand upon evidence based best practices in the delivery of out-patient mental health treatment and services.**

   Context: The components of known evidence-based best practice in community mental health are widely known to include at minimum: crisis intervention and pre-screening; mental health linkage case management and intensive case management; psychiatric evaluation and psychotropic medication management; medication management and prevention services; psycho social rehabilitation and skill acquisition; Mentally Ill Substance Abusers (MISA) services; supervised residential services; Assertive Community Treatment (ACT); consumer advocacy and education; employment/vocational training and placement; consumer involvement; cultural competence; research and evaluation of outcomes.

   a. Metro South will strive to make its constellation of services and resources as diverse and comprehensive as possible, filling any gaps that may currently exist.

   b. Support customer engagement, peer-led recovery methods, and general education.

5. **Establish an integrated service delivery system that includes the full array of public and private health and human services, law enforcement and courts, housing, jobs and economic development agencies that support mental health consumers, adequately funded.**

   Context: Mental health services alone do not meet all consumer needs. Stabilization and full recovery require ancillary services and resources located in the consumer's community. Providers of these other services must be accessible and appropriate to the needs of the mental health consumer.

   a. Increase training and funding for local law enforcement on mental health issues.

   b. Increase training for primary health care providers on mental health issues.

   c. Establishment and enhancement of MISA services.

   d. Integration of services provided by state agencies to consumers e.g. Department of Alcohol and Substance Abuse (DASA) and Division of Mental Health etc.

   e. Ensure that the mental health court system becomes accessible to private and public providers.

   f. Increase coordination with state employment services and supported employment opportunities.

   g. Increase connections with sources of affordable housing.

6. **Establish standardized mental health outcomes for the region and systematically track and monitor these outcomes.**

   Context: The IDHS Division of Mental Health (DMH) operates state mental health facilities and sets standards for and monitors utilization of its continuity of care agreements with private hospitals and other community mental health providers.

   a. This standard setting and monitoring role should continue and be enhanced such that data collected can be actively used to evaluate and improve the overall system of mental health services in the region.

   b. Maintain DMH's role as Network Manager particularly with regard to setting standards of care, monitoring and enforcing those standards.

   c. Develop a local outcome tracking system.

## Metro South Mental Health Planning Task Force

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AFSCME Council 31

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**Carl Bell, M.D.**
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# UNIVERSITY OF ILLINOIS AT CHICAGO

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December 18, 2008

Jeffrey M. Schoenberg, Co-Chair
Richard P. Myers, Co-Chair
Commission on government Forecasting and Accountability
703 Stratton Office Building
Springfield, IL 62706

Dear Chairmen Schoenberg and Myers:

Dr. Tamar Heller, Director of the Institute on Disability and Human Development, College of Applied Health Sciences at the University of Illinois at Chicago, asked me to forward to you written copies of her testimony given on December 11th at Howe Developmental Center. Also included is a review of the literature on the impact of placements of individuals with developmental disabilities out of institutional settings into community programs.

Thank you for the opportunity to provide this information.

Sincerely yours,

Leslie Ware Chapital

Leslie Ware Chapital
Assistant to the Director

Enclosures

**Testimony of Tamar Heller, Ph.D.**
**Illinois Disability Services Committee**
**December 11, 2008**

My name is Tamar Heller. I am the Director of the Institute on Disability and Human Development (IDHD), the University Center for Excellence in Developmental Disabilities for the State of Illinois. For the past ten years our center through the work of David Braddock, Rick Hemp (now at the University of Colorado) and Mary Rizzolo (IDHD) has worked on a project called the State of the States in Developmental Disabilities. In addition I have been involved in studying the impact of community placements on the lives of adults with developmental disabilities.

We know from the research that that individuals with developmental disabilities benefit from movement to community placements. Fears of increased mortality and health decrements are not substantiated in the literature. Furthermore a large body of evidence exists that residents benefit from community placements in regard to improvements in adaptive behavior, skill development, life satisfaction, and autonomy. Furthermore, families, who often oppose these placements initially report higher satisfaction with the community placements after the move than with the institutional placements.

Yet, as highlighted in the work of the 2008 State of the States report and from a report by David Braddock and Richard Hemp funded by the Illinois Council on Developmental Disabilities we know that Illinois has fallen behind in its commitment to community placements. The following are highlights from these reports:

**1- Illinois Over-Relies on Developmental Centers and Private Institutions for 16+ Persons**

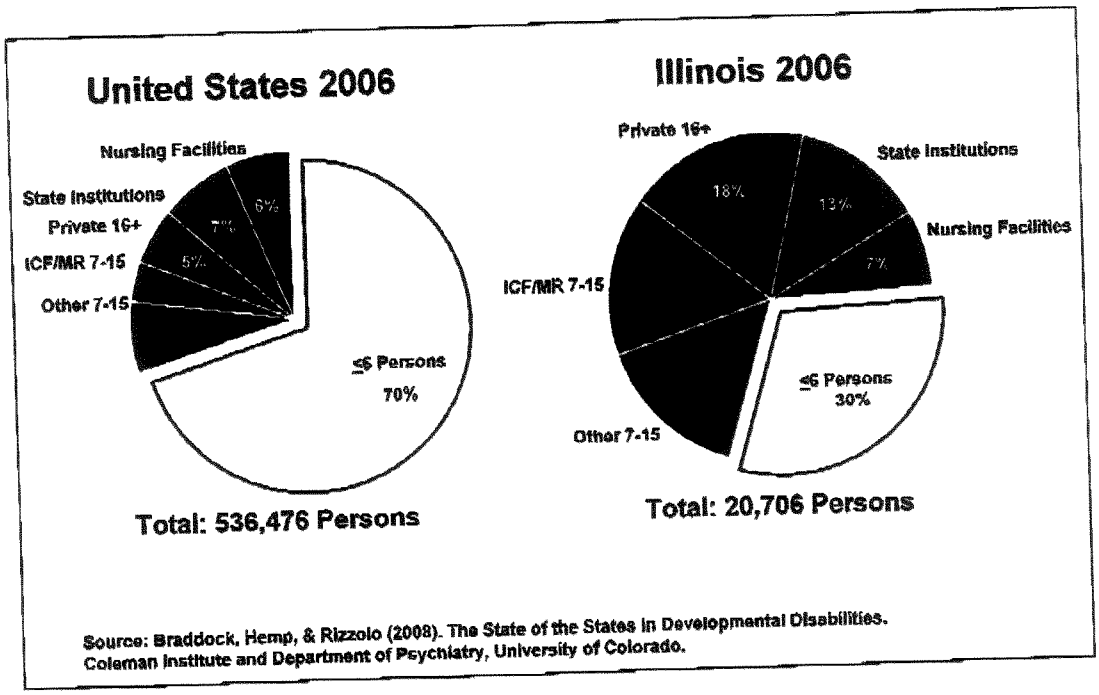
- Illinois has made some progress in the past few years in downsizing congregate care settings (settings for 16 or more). However, our utilization rate for state-operated institutions in 2006 is still over 60% above the U.S. rate, and three times the rate for the five Midwestern comparison states combined[1].
- In 2006, use of all public and private DD institutions in Illinois was 85% above the U.S. average, and 75% above that of the five comparison states combined[2].

**2- Illinois Allocates Comparatively Limited Resources for Community Services**

- In 2006, Illinois ranked LAST among all 50 states and DC in use of settings for six or fewer. Only thirty percent of Illinois' DD residential placements were in settings for six persons or less versus 70% in the U.S. and from 69-90% in the comparison Midwestern states.

[1] Aggregate institutional utilization: Total state institution census for the five comparison states, divided by the total general population of the five states.
[2] Total public and private institution census for the five comparison states, divided by the total general population of the five states.

- A comparatively large component of Illinois' "community residential facilities" are large group homes for 7-15 persons. They made up 31% of all out-of-home placements in the State in 2006, compared to only 11% in the U.S. and 10% in the comparison Midwestern states combined.




- Illinois ICF/DD spending in 2006 was 66% greater than HCBS Waiver spending. This is in dramatic contrast with the U.S. and all five Great Lakes comparison states, in which the large majority of funding is associated with the Waiver. Besides Illinois, only seven states -- Arkansas, Iowa, Mississippi, New Jersey, North Carolina, North Dakota, Texas, and the District of Columbia -- spend more for the ICF/MR program than for the HCBS Waiver.
- Illinois ranked 47th in federal-state Waiver spending per capita. Only Texas, Nevada, Georgia, and DC were below Illinois.

Mary Rizzolo Testimony April 16, 2008

The following are a list of selected recommendations from the forthcoming Braddock and Hemp report.

1 - **Continue to reduce reliance on the remaining nine state-operated institutional facilities and the large private ICFs/DD.** Medicaid ICF/DD resources should be reallocated to the HCBS Waiver.

2- **Expand Community Services and Related Supports to Address the State's Waiting List and Aging Caregivers**

- There are currently over 6,000 persons with DD on the Illinois waiting list for residential services (over 2,200 of these are designated as "emergency" needs). The need for additional Waiver services will continue to increase rapidly due to growing numbers of aging caregivers in the State.

3- **Develop a Plan to Significantly Strengthen Community Services Infrastructure**

- A multi-year plan should be developed to increase funding for community-based services and supports. The plan would incrementally increase Illinois spending to match the average state's expenditure for DD community spending by 2020.

With your help, we can make Illinois a better place to live for people with disabilities. We don't have to be 51st!

**Review of Outcomes Studies on Community Placements**

Tamar Heller, Abby Schindler, & Mary Rizzolo
University of Illinois at Chicago

The literature on the impact of placements of individuals with developmental disabilities out of institutional settings into community programs has focused on three broad areas, mortality, quality of life, and cost.

**Mortality**. Findings on mortality have garnered considerable attention. *In a review of 11 studies between 1960 and 1997 examining the impact of community placement on mortality of residents with developmental disabilities, Hayden (1998) found no evidence of increased mortality for residents moving into the community*. Some studies, such as the Pennhurst studies 1978-1989, found that mortality rates were lower in the community (Conroy & Adler,1998). She noted that the only studies that found higher mortality in the community were the studies by Strauss and his colleagues of the California data (e.g., Strauss, Kastner, & Shavelle, 1998). This study found that among 22,576 adults receiving services in California, 1985-1994 mortality rates (adjusted for age and level of functioning) were 72% higher in the community than in the institutional setting.

In an effort to replicate these findings, O'Brien & Zaharia (1998) also analyzed the California placement data. They found that from 1993-1995 community placements were not associated with increased risk of death. In fact, in 1993 and 1994 rates were lower in the community (adjusting for mobility , self-help skills, and level of MR) than in the developmental center. They did find higher mortality in the community in 1991 and 1992 (before the Coffelt period). The strongest risk factors for mortality were self-help skills, low motor skills, and dependence on technology, not residential placement. They criticized the Strauss studies since they found different results in number of deaths during the same period (1952 placements in 1.2 years and 34 deaths April 1993 to Dec. 1995 versus 1878 placement in 1.4 years and 45 deaths for the same period plus 45 days). They had concerns about accuracy of the data. The Strauss studies are widely criticized regarding their conclusions. They combined different types of community placements (including nursing homes, which often have worse outcomes), failed to include quality of life outcomes, and failed to measure quality of health care. These studies generally did not explain the process whereby higher mortality occurs. Also, it is difficult to impute causation by these studies, as they did not measure the same people longitudinally.

To correct these criticisms, a longitudinal study of mortality following deinstitutionalization from the North Princeton Developmental Center in New Jersey was conducted (Lerman, Apgar, & Jordan, 2003). The researchers found no increased risk in community placements, when controlling for critical initial risk variables (e.g., age 60 years and older, having epilepsy, low self-care abilities, and one or more medical conditions). Only nursing home placement was associated with increased risk.

**Quality of life.** Many studies have reviewed the impact of community placement on various aspects of quality of life of the individual with developmental disabilities. The

dimensions examined include 1) behavioral outcomes, 2) community participation, 3) satisfaction of families, 4) satisfaction of residents, 5) resident self-determination, and 6) other dimensions of well-being.

Overall, most of the studies have reported improvements in adaptive behavior after community placements. This conclusion has been reached in several review articles including Larson & Lakin's (1989) review of 18 studies; Kim, Larson, & Lakin's (2001) review of more than 250 studies on this topic, and Lynch, Kellow & Wilson's (1997) meta-analysis of 11 studies of specific adaptive behavior skills. The Lynch study found that self-care, communication, academic, social skills, and community living skills improved as did physical development. A literature review in the United Kingdom and Ireland concluded that deinstitutionalization was associated in most but not all the studies with increases in adaptive behaviors and reductions in observed challenging behavior (Emerson & Hatton, 1996). A study in New Jersey showed gains in self-care competencies, while institutional living was significantly related to losses in multi-cognitive functioning over a period of 27 months (Apgar, Lerman, & Jordan, 2003).

Other findings reported after deinstitutionalization have included the following:

1. Improved community participation (Conroy, 1996a;Emerson &Hatton, 1996; Raynes, Wright, Shiell, & Pettipher, 1994; Young et al., 1996), confiding relationships (Forrester-Jones et al, 2006), family phone contacts, and productivity (Apgar et al, 2003)
2. Improved self-determination and autonomy (e.g., Emerson & Hatton; Stancliffe & Abery, 1997; Wehmeyer& Bolding, 2001)
3. Improved satisfaction of families, who often opposed community placement initially (reviewed by Larson & Lakin, 1991). Families of those who moved were more likely to say that consumer life quality (material well-being, productivity, personal safety and health) was better in community residences and that life was better for their relative than in the institution.
4. Greater life satisfaction reported by residents (who can reliably be interviewed) after moving to a community setting from an institutional setting (Apgar et al, 2003)

The study of the Hissom closure (in Oklahoma) (Conroy et al., 2003) found that among 254 individuals who moved from 1990 to 1995, there were improvements in adaptive and challenging behaviors, participation in employment, number of hours of developmentally oriented services, opportunities for integration, frequency of contact with relatives, and lower use of anti-psychotic medications. While there was a greater difficulty in accessing health care, the urgency for health care needs declined. People had serious challenges with over 73% having severe to profound intellectual disabilities.

*Taken overall, I believe there is no clear evidence that deinstitutionalization of adults with developmental disabilities results in higher mortality for adults with developmental disabilities. Furthermore, there is a large body of literature indicating improvements in quality of life for these residents in community placements. The research from the two*

*closures in Oklahoma and in New Jersey have particular relevance to downsizing of institutions as they also entailed transfers of residents with severe levels of disability.*

**Cost**

The average cost of a state institution in the United States is $171,355 per participant, in comparison to $40,051 per participant in the Home and Community-Based Services waiver. However, the reduced cost of community care can be overestimated. For instance, while the population of state institutions has decreased by over 80% since 1976 in the US (Prouty, Coucouvanis, & Lakin, 2007), the per person cost of institutions continued to rise during this same time period, meaning that decreasing state institution populations by 74% only yielded real dollar savings of 24% (Lakin & Stancliffe, 2007).

Cost savings from deinstitutionalization are achieved through:

- The elimination/reduction of the high costs of operating a large state operated developmental center which is usually built for more people than the number that live there at the time of closure.
- Shifting some of the fiscal responsibility from the state to the federal government (i.e., from state tax revenues to SSI)
- Increases chances that individual will gain employment in community
- Leverage less costly community services (social, educational, recreational)
- Avoids the high costs of remodeling older institutions to meet federal standards (Braddock, 1991a, 1991b).

Since institutional and community services differ in the characteristics of the population, and the array of services provided, the most meaningful comparison of institutional and community services must be found in the deinstitutionalization outcomes research (Stancliffe et al., 2004). Cost comparisons from this research have shown that institutional services are more costly than those in the community (Campbell & Heal, 1995; Schalock & Fredericks, 1990). However, these costs reflect the substantially lower wages paid to direct support professionals at community agencies (Stancliffe et al., 2004). In 2004, the median hourly wage for personal assistance workers in the US was only $8.40 (Kaye, Chapman, Newcomer, & Harrington, 2006), about $1.50 less than entry level food service positions.

A New York state commissioned study found that post-closure per diems were only about 9% lower than pre-closure costs (New York OMRDD, 1990). Community spending levels in New Hampshire, Pennsylvania, and Connecticut ranged from 80% to 86% of their states' institutional costs (Brown et al., 2001; Conroy, 1996b).

A 12-year follow up on 273 individuals with intellectual disabilities who moved from a hospital setting to community care in England revealed that the mean cost of community-based support exceeded the costs of providing care in hospital placements by £163 per week the first year, and still remained £29 per week more than the average hospital cost 12 years after deinstitutionalization (Hallam et al, 2006). However, the same group experienced increased quality of life and quality of care.

**Active Treatment and Habilitation Planning versus Person-Centered Approaches**

Sweeping changes have occurred in regard to philosophy and approach to care for people with developmental disabilities (see Bradley, 1994). Past system reforms have included changes in the team approach to service delivery; the intermediate care facility (ICF/MR) model and its active treatment guidelines, the individual program plan, and interdisciplinary rather than multidisciplinary assessment. However, these approaches have been criticized as "inconsistently producing desired levels of individualization, skill acquisition, maintenance, self-direction, and reductions in problem behavior" (Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004, p.64).

Reforms in the field have emphasized more person-centered planning approaches. These are based on the premise that that people with disabilities should enjoy life in the community. The focus is on reducing social isolation, promoting friendships, and increasing autonomy, competence, social contribution and respect (Mount, 1994). Common criticism of the individual program plans and active treatment guidelines are that they tend to focus on deficits and disregard more global quality of life and long-range lifestyle enhancement (Stancliffe, Hayden, Larson, & Lakin, 2002). Hence, programs such as the Essential Lifestyle Planning approach (Smull, 1996) are more likely to take into account the individualized needs of residents in the context of their preferences, targeted skill developments to promote community living, and their overall needs in the community. While less detail-oriented than active treatment plans, it is much more focused on helping a person live a meaningful life that fits with his or her desires. A 2004 study in New York showed successful outcomes to persons moved out of Willowbrook into the community using a person-centered approach to planning. (Holburn et al., 2004). This process also resulted in better outcomes for residents including increases in autonomy, choice-making, daily activities, relationships, and satisfaction.

**Consumer Direction**

A significant reform to service delivery models is the inclusion of consumer-directed services and supports, which have grown dramatically over the past decade, both in the United States and internationally (Tilly, Wiener, & Cuellar, 2000; Tritz, 2005; Lundsgaard, 2005). Relatively few empirical studies have evaluated outcomes of consumer-directed supports for adults with I/DD., studies comparing consumer-directed and agency-directed services which focused primarily on individuals with physical disabilities (National Council on Disability, 2004) found that consumer directed services resulted in greater service satisfaction (Beatty et al., 1998; Benjamin and Matthias, 2001; Benjamin et al., 2000; Benjamin et al., 1999; Doty et al., 1996); and fewer unmet service needs (Benjamin & Matthias, 2001; Benjamin et al., 2000; and Foster et al., 2003). In general, studies have reported no significant differences in health status (Foster et al., 2003) or safety (Beatty et al., 1998 and Foster et al., 2003). However, some have reported psychological benefits concerning feelings of empowerment (Beatty et al, 1998) and perceived quality of life of individuals with disabilities (Foster et al., 2003).

The few studies that examined the impact of a consumer-directed program on individuals with I/DD found benefits in community participation and employment over a four year period (Caldwell & Heller, 2007; Heller, Miller & Hsieh, 1999), and decreased institutional placements over a period of 8 years (Heller & Caldwell, 2005).

Consumer-directed supports for people with I/DD have also focused on the impact of support on families. Among families of persons with I/DD, outcomes of consumer-directed programs include greater satisfaction with services, fewer unmet needs, and fewer out-of-pocket expenses for disability services (Caldwell, 2005; Heller, Miller, & Hsieh, 1999). Other outcomes for families include reduced feelings of stress and burden, greater self-efficacy, better access to healthcare, more opportunities for employment, and improved social and leisure opportunities (Caldwell, 2005; Caldwell & Heller, 2003; Heller et al., 1999; Herman, 1991; 1994; Meyers & Marcenko, 1989; Zimmerman, 1984). Among lower income families, benefits also include better mental health of caregivers and increased self-determination of individuals with disabilities (Caldwell, 2005).

**General Guidelines and Principles for Practice**

The relocation process should be designed as a seamless system wherein staff of the developmental center and families/guardians have input and provide information to staff at the receiving programs and providers. The process should have follow-up services built in that allow for input from developmental center staff and other concerned people during the 30 days following the transfer, the period that is most likely to be disruptive to the residents. Ongoing communication between developmental centers and receiving residences should occur prior to the move and within the 30 days after the move. Developmental center staff should remain available even after the 30 day period. Strategies to improve planning, communication, and oversight include the following:

- Develop a seamless relocation plan with a timeline, strategies for involving community agencies and other stakeholders, resources needed, list of residents and their needs, notification process, plan for alternative living arrangements that can address each individual's ongoing needs.
- Parents, families and guardians need to be informed of the closure and placements throughout the process.
- The community system must have a plan to provide supports needed including the capacity to support individuals with complex medical or intensive behavioral needs.
- A person centered community integration plan (CIP) for each individual should be developed to outline the plan for providing appropriate supports in the community setting. It should be followed by a 30 day review and there after annually. It should be based on a person-centered plan (such as the Essential Life Planning or other individualized planning tools). The CIP should focus on helping the person plan for a "meaningful life". It should emphasize choice-making, goal attainment and development of skills facilitating community participation.

- This person centered plan should involve administrators and staff from the developmental center and the receiving facilities, families, guardians, and the individual with disabilities.
- Minimize disruption by minimizing internal transfer of residents and staff in the developmental center and community placements.
- Give parents, guardians, and the individuals opportunities to visit the future placements and communities and address their concerns and preferences.
- Involve parents and people with disabilities who have been through the process of community placements to help inform others.
- Provide employee counseling and job placement services for employees at the developmental centers.
- Mechanisms should be developed and in place for sufficient preparation and oversight of community placements. In addition to state oversight systems, guardians and families should also provide oversight, so that their concerns and suggestions can be addressed.
- Staff in the community system need to be adequately trained to support individuals moving from the developmental centers. The staff from the developmental centers have insight into the unique needs of each individual and can convey these needs to the community staff.

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