LINCOLN DEVELOPMENTAL CENTER

The Politics of Closing a State Institution: Vulnerable People Fall Victim to Special Interests

A Report by the Abuse Investigation Unit
at Equip for Equality

Advancing the human and civil rights of
people with disabilities in Illinois

MISSION

Established in 1985, the mission of Equip for Equality is to advance the human and civil rights of people with disabilities in Illinois. Equip for Equality is a private not-for–profit legal advocacy organization designated by the Governor to operate the federally mandated protection and advocacy system (P&A) to safeguard the rights of people with physical and mental disabilities, including developmental disabilities and mental illnesses.

SERVICES, PROGRAMS & PROJECTS

Equip for Equality is the only comprehensive statewide advocacy organization for people with disabilities and their families. All individuals with a disability in Illinois (as defined by the ADA) are eligible for services, including children, senior citizens, and individuals in state-operated facilities, nursing homes, and community-based programs.

Self-Advocacy Assistance offers free, one-on-one technical assistance to inform individuals about their rights, alternative options and strategies, and steps they may take to advocate on their own behalf or on behalf of a family member.

Legal Services provides free legal advice and representation in administrative proceedings and federal and state court. Also engages in systems and impact litigation.

Training Institute on Disability Rights provides education through seminars for people with disabilities and their families. Seminar topics include rights and responsibilities under the Americans with Disabilities Act, protections against employment discrimination, guardianship, advance directives and special education rights.

Public Policy Advocacy achieves changes in state legislation, public policies and programs to safeguard individual rights and personal safety, enhance choice and self-determination, and promote independence, productivity, and community integration. Drafts and secures passage of state legislation and participates in state regulatory and policymaking processes. Also undertakes in-depth policy research and reform projects on complex issues that have a significant impact on the lives of people with disabilities.

Abuse Investigation Unit works to prevent abuse, neglect and deaths of children and adults with disabilities in community-based programs, nursing homes, and state institutions. Works with public investigatory agencies to improve their performance and coordination with each other; conducts investigations of abuse and neglect cases; alerts service providers to dangerous conditions and practices. Funded by Congress as national demonstration project.

Last year, over 5,600 individuals benefited from the many programs and services of Equip for Equality. In addition, thousands of individuals benefited from its public policy and other systems change initiatives.

LINCOLN DEVELOPMENTAL CENTER

The Politics of Closing a State Institution: Vulnerable People Fall Victim to Special Interests

A Report by the Abuse Investigation Unit
at Equip for Equality

This publication is made possible by funding support from the *Centers for Medicare and Medicaid Services,* the *Illinois Department of Public Health* and the *Illinois Department of Human Services.* The contents of this publication are solely the responsibility of Equip for Equality and do not necessarily represent the official views of any of these agencies.

ILLINOIS REGIONAL OFFICES

Northeastern Region (Chicago)
20 N. Michigan Ave., Suite 300
Chicago, Illinois 60602
312/341-0022
800/537-2632
800/610-2779 TTY
312/341-0295 FAX
Se habla Español
American Sign Language

Northwestern Region (Rock Island)
1612 Second Ave., P.O. Box 3753
Rock Island, Illinois 61204
309/786-6868
800/758-6869 Voice/TTY
309/786-2393 FAX

Central/Southern Region (Springfield)
235 S. Fifth St., P.O. Box 276
Springfield, Illinois 62705
217/544-0464
800/758-0464 (Voice/TTY)
217/523-0720 FAX

Website: **www.equipforequality.org**
e-mail: **contactus@equipforequality.org**

In October 2001, by securing additional resources, Equip for Equality was able to establish an Abuse Investigation Unit to address systemic issues of abuse and neglect affecting individuals with disabilities in any setting, licensed or unlicensed, including state-operated facilities, community agencies, and nursing homes. Lincoln Developmental Center (Lincoln), a state-operated developmental disabilities institution, was the first facility in which the Investigation Unit conducted an in-depth examination of the problems and concerns seriously affecting the health and safety of the individuals residing at that facility.

Summary of Activities, Findings, and Conclusions

In October 2001, Equip for Equality began a series of unannounced visits to Lincoln and began to review extensive numbers of documents related to the incidents and events at Lincoln that had resulted in multiple injuries and deaths. Equip for Equality's activities complemented, and were coordinated with, the activities of state agencies involved in monitoring conditions at Lincoln. Equip for Equality staff conducted exit interviews with Lincoln administrators and shared concerns with the Illinois Department of Public Health, the Office of Developmental Disabilities, and the Office of the Inspector General for the Department of Human Services.

Equip for Equality's investigation documented that on its best day, Lincoln only warehoused its residents, offering little in the way of programming and active treatment essential to an individual's well-being. At other times, Lincoln was a dangerous place to live, where residents were at risk of serious injury and even death.

In more than 200 hours of independent monitoring and observations, and the review of hundreds of State records, Equip for Equality documented an extensive history of egregious abuse and neglect resulting from the appalling treatment and condition that the residents were compelled to endure year after year, including the use of a medieval-looking helmet, a resident being immobilized by mechanical restraints on her hands and ankles who was nearly choked to death by staff, and deaths that were preventable had residents been properly supervised.

Despite the contention of those who supported Lincoln, that it was basically a good institution that should remain open, the incidents described in this report demonstrate that this was simply an illusion. The observations and records related to the conditions at Lincoln confirmed the conclusion made by the State that Lincoln was a dangerous facility that needed to be closed. **All efforts by the State to improve conditions and the treatment of the residents at Lincoln failed, despite the substantive infusion of new resources into the facility.**

Lincoln's proponents, primarily the American Federation of State, County and Municipal Employees union (AFSCME), the business community, local legislators, and vocal family members, opposed the call for closure, due to the economic impact this would have upon the community and the groups who depended on Lincoln for their livelihood and on a misguided belief that Lincoln was no worse than other institutions. In contrast, Equip for Equality continued to focus attention on the tragedies and despair inside of the institution and the continual risks to the safety and well-being of the individuals living there.

Cited by the State as more problematic than any other state-operated developmental disabilities center, Lincoln remained a miserable failure until its closure, routinely subjecting its residents to the worst forms of abuse, profound neglect, and even death. On August 31, 2002, the State of Illinois closed the Lincoln Developmental Center.

THE LINCOLN DEVELOPMENTAL CENTER

Lincoln first opened its doors in 1877. By the 1980s, Lincoln housed approximately 450 individuals and was one of the 11 state-operated institutions for individuals with developmental disabilities in Illinois. Lincoln, spread over a several-acre campus, maintained 12 residential buildings along with a series of buildings for administrative staff, training programs, maintenance, and the like. The majority of the residents at Lincoln functioned in the severe to profound range of mental retardation with many nonverbal residents. A number of residents were not ambulatory, and some had complicated medical conditions that often resulted in compromised respiratory systems. At the time of Lincoln's closure, it cost $35 million per year to keep the institution open.

Lincoln's history is replete with abusive practices and profound neglect resulting in a litany of horror stories.

For more than two decades prior to its closure, state and federal regulators focused substantial attention on Lincoln, frequently citing the institution for problems related to the care and treatment provided to the individuals living there. Not even the threat of decertification and the loss of federal funding could prompt the changes necessary to prevent staff abuses, resident injuries, and deaths.

In the 10 years prior to Lincoln's closing, it continued to be plagued by problems resulting in numerous resident injuries and deaths. In 1993, chronic problems with the abuse of the individuals living at Lincoln led to a covert investigation by the Illinois State Police. That investigation resulted in the departure of 11 staff members and the conviction of one staff member for aggravated sexual assault of a resident. In 1995, a resident left behind in the community after an outing was found drowned in a public swimming pool. In 1998, a resident died after asphyxiating and suffocating on his own vomit from being restrained face-down for more than 35 minutes by five staff members.

Since the mid-1990s, the Illinois Department of Public Health (IDPH), the state Medicaid survey agency, cited Lincoln for failing to protect its residents and failing to provide appropriate treatment and programming more times than any other state-operated developmental disability institution. IDPH also recommended Lincoln for decertification more times than any other similar institution.

In spite of the infusion of extraordinary resources, Lincoln remained a dangerous facility until its closure.

In an effort to address the long-standing problems at Lincoln, the Department of Human Services (DHS) began to commit extraordinary resources and attention to Lincoln. From 1998 until Lincoln closed, those resources included the following:

- **New and experienced leadership** at the institution;
- **Over 3,500 hours of state employees' time being redeployed** to Lincoln to address issues of abuse and neglect, safety, health, programming, and active treatment;
- **On-site clinical, administrative, consultative, training and oversight services** by the DHS staff, facility directors, medical directors, and directors of nursing;
- **Monitoring by DHS and IDPH** virtually every day from the fall of 2001 until its closure to help ensure resident safety;
- **Extensive and ongoing retraining of staff** in numerous areas by local and national experts, including pica (ingestion of nonedible items) behavior management, abuse and neglect prevention and reporting, active treatment and programming, de-escalation techniques, and infection control;
- **Dramatic reductions in resident population**, eventually giving the institution the highest staff-to-resident ratio of all Illinois state-operated developmental disability facilities.

However, providing extraordinary resources to improve Lincoln failed to create a safe environment with appropriate sustained programming. The pattern of incidents involving the same staff failures, resulting in more serious injuries to residents within short periods of time, demonstrated the existence of a culture that was not amenable to change. Even when staff should have been at their very best, the same kinds of incidents that jeopardized resident safety and well-being continued at Lincoln.

In the two years prior to Lincoln's closure, the reported incidents at Lincoln appeared to increase in frequency and severity, routinely resulting from staff failure to supervise and monitor residents, leading to serious injuries, hospitalizations, surgeries, and deaths. Moreover, the incidents demonstrated the staff's inability to sustain any benefit from the ongoing training or to implement appropriate plans and strategies to address the ongoing problems threatening the health and safety of the residents.

In **September 2000**, the federal **Centers for Medicare and Medicaid Services** (CMS) of the United States Department of Health and Human Services **and IDPH determined that a crisis**

situation existed at Lincoln which threatened the health and safety of the residents as a result of two incidents. The first incident involved **staff failure to properly report an allegation of a staff member's purchase of illegal drugs in the presence of residents** and then the failure of Lincoln to protect residents from the accused staff during the investigation. The second incident involved **numerous medication administration errors** by one nurse found to be incompetent by the surveyors.

Further incidents during the fall of 2000 included the **October death of a resident from a prolonged seizure** due to the lack of the proper medication and inadequate health care services at Lincoln. In November, **a resident wandered away** from Lincoln unsupervised because of a series of errors by multiple staff and the lack of facility procedures to address the availability of keys, securing of doors, use of alarms, supervision of residents, and staff accountability. The resident was able to take a key that he kept until the following week, when he **stole a semi-trailer truck and drove toward Bloomington**. The resident was returned to Lincoln unharmed the next day.

In response to the incidents in 2000, policies related to staff supervision of residents and accountability were developed at Lincoln. Professional staff from other state-operated institutions and the Office of Developmental Disabilities conducted trainings on the policies and increased site visits to Lincoln. In spite of the increased activity by outside professionals, the reported incidents at Lincoln continued unabated, with similar staff failures leading to more tragic consequences.

- **Jan. 2, 2001. A resident was found submerged under water in the bathtub** after being left unattended, but she survived.

- **March 8, 2001**. A resident with pica behaviors (ingestion of nonedible objects) **swallowed pills taken from an employee's purse**. His stomach was pumped and he was stabilized.

- **March 21, 2001**. Using a bed sheet, a **Lincoln nurse choked a resident** who was under full mechanical restraints. The resident lost consciousness but was revived. Staff failed to report the incident until three weeks later. The nurse had, as part of a termination agreement with another state-operated facility, agreed never to work at a state-operated facility again but subsequently became employed at Lincoln. Criminal aggravated battery charges remain pending against the nurse.

- **April 12, 2001**. A resident with pica behaviors was **hospitalized for ingestion of a pen cap** from a felt-tip marker. He **required surgery** to remove the cap.

- **June 20, 2001**. A resident with pica behaviors was taken to the hospital, where he later **underwent surgery to remove several latex gloves and cloth** material he had eaten.

- **July 16, 2001**. The same resident who ingested the pen cap in April was **hospitalized again, this time for ingestion of plastic dominoes**. The resident endured **multiple surgeries** to remove the dominoes and suffered serious complications followed by a lengthy hospital stay.

- **July 21, 2001**. The resident who ingested pills taken from an employee's purse on March 8, 2001, **ingested another staff member's medication** that he found in a purse left in the back seat of the car in which he was riding during a community outing. **This time, the resident died from the drug overdose**. Although the staff member in the second incident found her empty medication container prior to the resident's death, she failed to come forward with information regarding the amount or type of medication that the resident had ingested.

In **August 2001, IDPH found** that the **conditions at Lincoln** that led to the incidents between March and July **presented an "immediate jeopardy" to the health and safety of the residents.** IDPH again cited Lincoln for failing to sufficiently protect the residents from harm **in that Lincoln:**

- **Failed to provide appropriate and necessary interventions to prevent serious physical injury resulting from pica behaviors;**
- **Failed to ensure implementation of individual program plans** identifying appropriate interventions for pica behaviors in order to meet the individual needs of the residents;
- **Failed to protect residents from physical harm inflicted by the staff**;
- **Failed to ensure that the residents were not subjected to physical abuse** as a result of the staff's failure to intervene when necessary to meet the individual needs of the residents;
- **Failed to implement policies and practices to protect residents** from neglect and abuse;
- **Failed to ensure that incidents of abuse were properly reported** by facility staff;
- **Failed to promptly notify guardians** of an allegation of physical abuse; and
- **Failed to ensure that a sufficient number of staff were present** to provide the necessary level of supervision for residents requiring a "total level of supervision," meaning a continuous level of direct staff supervision at all times in all environments.

In **September 2001**, **IDPH again determined that the residents at Lincoln were in "immediate jeopardy"** when staff left a resident who was exhibiting pica behaviors alone on numerous occasions. Reports of additional incidents related to the staff's failure to properly supervise residents continued in September, including the following:

- **Two Lincoln staff members failed to observe a resident with pica behaviors bite a hole in his pants, swallow the material, and handle small objects,** even though staff were to be watching the resident at all times.

- **Another resident** identified as previously ingesting lint, string, and threads, and who was also **to be in eyesight of a Lincoln staff member at all times, was** escorted to a bathroom but **left alone** inside, where an unlocked cabinet contained washcloths.

State records also reveal a horrifying occurrence in September, later substantiated by State investigators, which illustrates the depth of cruelty inflicted upon residents. In that incident **a staff member, apparently angered by a resident's request to use the washroom, refused to allow her to use the washroom and then, after the resident soiled herself, forced the resident to lick up her own urine from the floor.** The resident was then forced to clean up the remaining urine from the floor with her own clothing, which she stayed dressed in for some period of time.

In early **October 2001**, during a survey to follow up on the conditions identified in August, IDPH found that many of the original conditions that resulted in the facility's being cited remained uncorrected, and **additional serious problems** were discovered, **which led to a recommendation that Lincoln be decertified and the federal funding terminated because Lincoln**:

- **Continued to fail to protect residents from abuse** and neglect, demonstrating a systemic and serious problem;

- **Continued to fail to provide staff in sufficient numbers to protect the health and safety of the residents,** to provide the requisite level of supervision in order to provide appropriate interventions, or to promote acquisition of skills;

- **Continued to fail to provide a safe environment** for residents with documented pica behaviors;

- **Failed to provide residents with opportunities to make choices** and failed to ensure that residents were involved in activities which address their individual needs;

- **Failed to provide sufficient direct-care staff for continuous active treatment**, needed care and services;

- **Failed to ensure that residents had freedom of mobility**;

- **Failed to ensure that injuries of an unknown origin were properly and thoroughly investigated**;

- **Failed to provide nursing services to meet residents' individual needs**; and

- **Failed to ensure proper sanitation of developmental materials and furniture** following incontinent incidents, and **failed to implement universal precautions in the handling of body fluids** of 144 individuals.

The specific problems uncovered by IDPH during the October review, which resulted in the decertification recommendation to the federal government, included the following incidents and observations:

- **Multiple injuries to residents as a result of an insufficient number of available staff**;
- **Multiple residents exhibiting pica behaviors** who were observed ingesting nonedible items such as pieces of clothing, lint on the floor in a toilet area, and string, without prompt staff intervention;
- **Residents exhibiting pica behaviors found in areas having unsecured cabinets** that contained nonedible items that could be ingested, such as plastic gloves, incontinence briefs, and toilet paper;
- **Residents exhibiting pica behaviors found in areas that had unsecured waste containers** with soiled incontinence briefs and used gloves; and
- **At least 15 residents with injuries** that were identified by staff as having resulted **from unknown origins,** even though such residents required a level of supervision necessitating one staff member being assigned to care for just that one resident, or total supervision, keeping the resident in eyesight of staff at all times.

In October 2001, Equip for Equality began a series of unannounced visits to Lincoln that continued until its closure. Equip for Equality spent over 200 hours directly observing at Lincoln and reviewing extensive documentation regarding incidents at Lincoln. Equip for Equality staff observed residents at Lincoln in various settings, including all of the residential buildings, several day programs, and the medically fragile unit. Within the residential buildings, observations were made while residents were in approximately 24 living units or areas, primarily in the day/activity rooms. Residents exhibiting pica behaviors were observed throughout the facility.

On October 19, 2001, after two days of observations, Equip for Equality advised IDPH of serious concerns resulting from the observations, which demonstrated that the conditions that had led to the decertification recommendation continued to exist, placing the residents at substantial risk of serious harm. Based upon its observations, Equip for Equality concluded that the efforts by Lincoln staff to intervene in response to pica and other maladaptive behaviors were not timely or consistent. Often staff failed to note pica behaviors, or when they did, failed to intervene in a timely manner. Staff also failed to remove from residents' easy reach nonedible items, such as dryer sheets, lint, string mops, pens with removable caps, belts, bottle tops, and various hygiene supplies that could be ingested by those with pica behaviors.

As a result, Equip for Equality strongly urged IDPH to engage in regular, ongoing monitoring activities at Lincoln while the State addressed the issues related to the long-term status of Lincoln. In response, IDPH began regular on-site monitoring at Lincoln.

In October 2001, Governor Ryan ordered the transfer of 90 residents from Lincoln, the appointment of a new leadership team, and 30-day assessments of Lincoln's progress in trying to abate the conditions that had led to the decertification recommendation by IDPH.

In spite of those actions, additional incidents occurred in October. State records reveal that a resident who was able to hide in a washroom was later found by staff with a foreign object inserted into his penis. During additional visits by Equip for Equality, a resident was observed attempting to eat a cigarette butt found in an unsecured garbage container, which went unnoticed by staff. Equip for Equality brought the resident's action to Lincoln staff's attention so that the cigarette could be removed from the resident's mouth. Equip for Equality observed residents swiping the floor and the bottom of their shoes and then inserting their hands into their mouths while other residents were observed biting their hands repeatedly or chewing on clothing or items found on the floor without staff intervention. Equip for Equality routinely observed a variety of nonedible and dangerous items, including supplies in an open laundry room that were visible and available to the residents with documented pica behaviors.

On November 5, 2001, Equip for Equality called upon Governor Ryan to close Lincoln due to its ongoing failure to address the serious safety and programming deficiencies that led IDPH to recommend decertification. Equip for Equality urged the State to close Lincoln in a timely manner to allow for a well-planned and orderly transition to community integrated living arrangements (CILAs) or other facilities, depending on individual preferences and needs, and to address critical transition issues.

In November 2001, IDPH again observed residents engaging in pica behaviors and noted the availability of harmful substances and the existence of the conditions that could result in serious injuries or further deaths. Accordingly, **IDPH again found the residents at Lincoln to be in "immediate jeopardy."** Two additional incidents involving residents with pica behaviors were also reported in November. One incident involved the ingestion of plastic wrap by a resident, which was later found in his stool, and the other incident involved the possible ingestion of a wooden game piece by another resident.

In late **November 2001, federal Medicaid funding of Lincoln was terminated,** which represented one-half of Lincoln's $35 million budget.

On December 4, 2001, Equip for Equality again called upon Governor Ryan to close Lincoln, citing the continuation of the potential for life-threatening injuries as documented by the ongoing incidents involving residents with pica behaviors and staff failures to properly address such issues. In response to the call for closure, Governor Ryan, in a statement to the media, asked Equip for Equality to act as an independent monitor at Lincoln, along with the State monitors, to ensure resident safety, and he ordered DHS to develop plans to either close Lincoln or substantially downsize it. The Governor also ordered the transfer of another 100 residents from Lincoln.

While Lincoln was successful in implementing a plan of correction so that federal funding was resumed, **in January 2002, Lincoln resumed its well-established pattern of making minor**

improvements to address adverse actions, but then resorting to a standard of care which again left residents at risk of serious injuries or death, as reflected by the following incidents:

- **A resident with pica behaviors was left unattended** by staff in a shower.
- **A resident with pica behaviors was observed leaving a classroom and walking out of the building without any staff**.
- **A resident with pica behaviors was observed alone, running away** from a residential building.
- **A resident with pica behaviors was left unattended so staff could assist another resident**.
- **A resident with pica behaviors attempted to grab cigarette butts from an open ashtray in a hallway** near a resident living area.
- **A resident with pica behaviors was able to snatch items from a garbage container**, stuff the items in his pocket, and go into a bedroom, closing the door.
- **Cloth underwear was left in an unlocked cabinet in an area with a resident with pica behaviors that included ingesting cloth and string**.

In January 2002, Equip for Equality testified at a joint hearing of the Disabled Community and Mental Health and Patient Abuse Committees of the Illinois House of Representatives, urging closure of Lincoln. Based upon further observations and monitoring activities, Equip for Equality called a meeting of the key state agencies responsible for the conditions at Lincoln because of its concern that the conditions appeared to be further deteriorating. In response to Equip for Equality's concerns and recommendations, DHS intensified its system of monitoring at Lincoln and IDPH maintained an ongoing presence at the facility. In February, the Governor ordered the transfer of an additional 150 individuals from Lincoln.

On multiple site visits, Equip for Equality observed residents whose respiratory needs were potentially compromised as a result of the staff's failure to properly position and maintain medical equipment, address infection control issues by timely removal of excessive water from oxygen tubing, and timely suctioning of secretions from tracheostomies. Although these specific concerns were presented to Lincoln staff, on return visits, Equip for Equality continued to observe the same staff failures to address the problems.

Throughout the remainder of 2002 until Lincoln's closure, monitors for IDPH or DHS were present on a daily basis. Nonetheless, the reported incidents, along with the 30 day assessments by DHS, demonstrated that Lincoln remained an unsafe facility, where the health and safety of its residents were continually at risk. Lincoln failed to meet minimum standards of care and safety mandated by federal and state regulations.

Even the death of the resident in July 2001 and the ongoing incidents related to pica behaviors did not cause Lincoln to review the environmental risk factors associated with the placement of residents with such behaviors. For example, the resident who snatched items from the garbage

in February 2002, and whose known pica behaviors included ingesting tobacco products, shared a bedroom with another resident who used and stored chewing tobacco in their bedroom. In March, the **resident with pica behaviors was taken to the hospital to have his stomach pumped after eating his roommate's chewing tobacco**. In May 2002, another resident who had been identified with pica behaviors, including the ingestion of tobacco, and who was to be in the eyesight of staff at all times attended day programming on campus near a staff break room where smoking was allowed. That **resident was able to leave her group unsupervised and ingest a handful of cigarette butts which she found in an open ashtray left out in the staff break room**.

In addition to the observations, Equip for Equality staff reviewed 15 months' worth of records related to reports of abuse and neglect and other reportable incidents at Lincoln, including reports related to the use of mechanical and physical restraints as well as other restrictions of residents' rights. Those records reveal that approximately 60 percent of the reported injuries sustained by residents were serious enough to require multiple sutures, or resulted in bone fractures, hospitalizations, or death.

In June 2002, Lincoln prepared for a final "do or die" full IDPH certification survey, which if Lincoln did not pass would leave it with no right to further hearing, administrative review, or appeal and would result in Lincoln's immediate decertification and the loss of federal funding. **At a time when Lincoln staff should have been at their very best, ongoing staff failures resulted in further incidents.** Those failures led to the following:

- **A resident who was known to engage in self-injurious behaviors**, including the insertion of items into body cavities, and **who was to be within staff eyesight at all times when awake and checked every 15 minutes when sleeping was found with a broken hanger inserted into his rectum**.

- **A resident who exhibited pica behaviors and who was to be within staff eyesight at all times was left in a washroom unattended**.

- **A resident who was known to insert objects into his nose and who was to be within staff eyesight at all times was able to leave his group unnoticed by staff and make his way to a day training site on the other side of the Lincoln campus**.

- **A resident diagnosed with pneumonia was found sleeping in his room while staff, who were to be aware of the resident's whereabouts** at all times, believed that the resident was attending a day training program and were **unaware that the resident had been in his room for several hours**.

Staff remarks about some of the most serious incidents caused by a lack of supervision, which resulted in death and the potential for serious injuries, were most disturbing. In response to the drowning of a resident in a public swimming pool, one staff remarked "accidents happen." Even after all the incidents related to the staff's failure to adequately supervise residents, the staff member responsible for keeping a resident in his eyesight at all times because of the resident's tendency to insert objects into body cavities described the resident's ability to leave a residential building unnoticed and walk across the campus to be "no big deal."

The June 2002 incidents occurred at a time when Lincoln's staffing levels provided the highest number of staff per resident ratio among the state-operated developmental disability institutions. **Citing the June incidents as the "last straw" for Lincoln, on June 10, 2002, Governor Ryan ordered the closure of the facility.**

Lincoln failed to provide residents with active treatment and programming.

Lincoln's record of providing active treatment and programming for its residents was as dismal as its record for providing a safe and secure environment. Lincoln failed to meet minimum program standards, the kind of ongoing active and appropriate treatment and programming necessary to meet an individual's goals and preferences, and to enhance skills or foster independence. Rather, **Lincoln chose to continually provide care that was merely custodial. Warehousing people with disabilities in that fashion is simply inexcusable. IDPH cited Lincoln repeatedly over the years for its lack of basic programming and active treatment as required by federal law.**

Equip for Equality observed residents during scheduled activity time in the day program on the Lincoln campus. The activities were not appropriate programming or active treatment. The activities did not appear to be based upon programming developed from individualized assessments but were simply group activities that many residents were not interested or involved in, resulting in some residents having nothing to do and others engaging in maladaptive behaviors. The activities, which included such things as painting, making wax shavings for candles, watching staff use a computer, paper shredding, and sanding wooden blocks, did not have any meaning or purpose for many of the residents and were not designed to meet individual goals, maintain or develop functional, age-appropriate skills, or foster independence.

While some Lincoln staff attempted to engage residents in activities, most staff failed to implement any sort of appropriate programming or activities that were of interest to the residents or were designed to meet their needs or abilities or were designed to maximize their level of functioning. For example, eight residents were observed in a room where two residents, with staff assistance, were shredding paper by inserting the paper into two machines. There was no effort by staff to involve the other six residents in the activity by doing such things as sorting paper for shredding, bagging the shredded material, or shredding paper by hand. Likewise, the room contained no other material or programming supplies available for resident use. Consequently, six residents had nothing with which to meet their individual goals and needs.

During nine months of monitoring activities, Equip for Equality observed Lincoln staff presenting information to residents that bore no relationship to the residents' experiences or skill levels such as:

- A staff member showing pictures of various presidents to severely cognitively impaired residents while attempting to explain the Cold War, while another staff member presented what he described as "marketing and economic" theories to other residents.

- A review of the daily programming schedule for the most severe and medically complex residents at Lincoln revealed an activity entitled

"orientation to manufacturing" and also included 60 minutes allotted to name recognition activities that consisted of each individual responding when staff called out their name.

Throughout the course of the monitoring activities, Equip for Equality continually observed across the entire Lincoln campus that:

- **Lincoln staff involvement with residents often commenced only when monitors from other agencies approached an area.**
- **Television appeared to be the most common form of activity** promoted by staff at Lincoln and often included programs that were of a provocative or violent nature.
- **Frequently residents were idle, restless, sleeping in chairs, or engaging in self-injurious and other maladaptive behaviors,** such as aggressively striking themselves or walls, or disrobing as a result of the lack of appropriate programming, while staff failed to intervene in an appropriate or timely manner.

During the late-afternoon, evening, and weekend observations in the living units, Equip for Equality saw virtually no programming or active treatment for the residents. Rather, residents had nothing with which to occupy their time. The "materials" that seemed to be most available to the residents were children's toys and included pieces of plastic that the residents placed in and took out of containers, a few puzzles, shape sorters, and the like. The materials were not age-appropriate, were devoid of meaning or purpose, and were not designed to further individual goals, maintain or develop functional, age-appropriate skills, or foster independence.

Some Lincoln staff appeared to be unaware of the nature and severity of the residents' conditions for whom they were responsible in spite of available information regarding the residents. Other staff complained that the resident-to-staff ratio was insufficient to allow for any meaningful activity, particularly in light of the serious safety risks presented by the residents exhibiting pica behaviors. A few staff expressed concerns regarding the lack of training, indicating that the high level of staff turnover resulted in "the trainees training the trainees."

Equip for Equality's efforts resulted in attention being focused on the safety and well-being of the residents.

The most frequently cited arguments opposing closure of Lincoln related to the economic impact to the community and the staff and that the facility was basically good. Proponents in support of keeping Lincoln open, rarely, if ever, addressed the treatment of the residents. When treatment was addressed, the proponents ignored the ongoing serious safety threats, including the injuries and the deaths that had plagued Lincoln for years. These proponents suggested that Lincoln was not as problematic as other institutions serving individuals with developmental disabilities in spite of State records and the findings of various agencies to the contrary.

Equip for Equality continued to focus the attention of the Governor, lawmakers, State agencies, and the public on the tragedies and despair inside of the institution and the continual risks to the safety and well-being of the individuals living there, by issuing public reports of its observations, calling for the closure of the institution, bringing together the responsible State agencies to address ongoing threats to safety, and testifying before lawmakers.

Implications for Illinois and Individuals with Disabilities

The individuals who lived at Lincoln had to endure an ongoing ordeal that resulted in serious injuries and deaths because of the long-standing abuses and profound neglect. Even worse, **in the midst of the ordeal, many lost sight of the reason why publicly funded services exist for individuals with disabilities**. Those services exist for the sole benefit of those to whom the services are provided, to enable individuals with disabilities to attain the highest level of independence and to participate in the community to the fullest extent possible. **Publicly funded services do not exist to support the staff of a facility, to provide economic support to the community, or to serve special interests**. The manner in which the crisis at Lincoln publicly unfolded, as reflected by the statements of the union, the Lincoln business community, and various political interests, demonstrated that many placed their own special interests above the safety and well-being of the individuals residing at Lincoln.

In order to ensure that the interests of individuals with disabilities are not compromised in favor of the special interests of a few, problematic facilities need to be identified quickly and sufficient resources need to be available so that such facilities can be independently and fully assessed and decisions related to their continued status can be made in a timely manner. Only then will another crisis compromising the health and safety of individuals with disabilities be prevented.

Even with the closure of Lincoln Developmental Center, Illinois continues to be one of the most heavily institutionalized states, ranking 43rd nationally, with 10 remaining state-operated institutions for individuals with developmental disabilities spread throughout the state. At the same time, Illinois continues to rank near the bottom nationally in its spending for community based programs, ranking 42nd. **The closure of the Lincoln Developmental Center has provided the State with the opportunity to follow the national trend of providing greater supports and services to a community-based system to allow individuals with disabilities to live in less restrictive and more integrated settings.**