LIFE AND DEATH IN STATE-OPERATED DEVELOPMENTAL DISABILITY INSTITUTIONS

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EQUIP FOR EQUALITY

I. Executive Summary

Across the nation a majority of states have been moving individuals with mental retardation and developmental disabilities who reside in large state-operated residential facilities into integrated, community-based housing. States that have enacted such changes have also provided a contemporaneous shift of resources away from the institutions and into the community setting. While such change is occurring throughout the nation, Illinois continues to favor the state-operated system despite a large body of irrefutable evidence documenting that large congregate settings create an environment of care that marginalizes people with disabilities, inhibits integration within society, fosters dependence and creates a culture of abuse and neglect that victimizes our society's most vulnerable members.

The report that follows provides an in-depth examination by Equip for Equality's Abuse Investigation Unit of the abuse, medical neglect and staff indifference leading ultimately to the tragic and senseless death of Brian Kent, an individual with developmental disabilities who lived at a state-operated institution for a short time. The Investigation Unit closely examined the events and records related to Brian's care at the Ann M. Kiley Developmental Center in Waukegan, Illinois, and the investigations conducted by state agencies, the coroner and law enforcement. The report also contains information on the Investigation Unit's examination of 12 additional deaths at some of Illinois' other state-run institutions, to illustrate the ongoing dangers embedded within the culture of Illinois' system of institutional care—dangers that have been documented historically but from which valuable lessons have either been lost or have never been learned.

The abuse, neglect and mistreatment reflected in the treatment that Brian and the other individuals received is a reflection of the care often provided in a large state-run institution—a system that frequently places higher value in protecting jobs, defending substandard care and warehousing people with disabilities than in providing meaningful and compassionate care that is fully integrated into the larger society. While the institutional system in Illinois is afforded tremendous resources, it is a system that routinely tolerates substandard care and fosters the worst forms of abuse and neglect. In a word, it is a system of care that is simply uncaring and inexcusable. The tragedies described in this report provide ample evidence that the state-operated developmental disability system is so plagued with problems that it is simply beyond repair.

Brian Kent

Until the age of 11, Brian, who was profoundly developmentally disabled, blind in one eye, visually impaired in the other, and non-verbal as a result of a severe hearing loss, lived at home with his family. As Brian grew older, he developed a compulsion to break glass, which over time increased and placed him at greater risk of substantial injury. While Brian's parents had successfully cared for Brian at home, they were afraid that there would come a time when they could not keep Brian from injuring himself. Consequently, the Kents began looking for a place for Brian to live close to home. Before coming to the Ann M. Kiley Center in Waukegan, Illinois, in July of 2002, Brian resided at a facility for children in Rockford and thereafter in an adult community facility in Galesburg, Illinois. When the Galesburg facility became unsuccessful because resources were not made available to meet Brian's need to have one staff member provide care solely for him, the facility told the Kents that a placement in a state-run institution had been secured for Brian. No other community-based options were made available for him.

Shortly before Brian was admitted to Kiley, his father was given an informational packet about the institution. In those materials Kiley espoused a commitment to maintain an environment free from physical and psychological harm, to provide support to each person to ensure his or her best possible health, to provide appropriate medical care and to create an environment free from abuse and neglect. Based upon Kiley's assurances, the Kents comforted themselves with the belief that the institution had round-the-clock staff who could provide the structure that Brian needed, experts available to respond to those situations beyond the Kents' ability to address, the resources to provide one-to-one care, and doctors and nurses available 24 hours a day. Such promises, however, would prove to be empty for Brian.

When Brian arrived at Kiley, he was energetic, active and healthy. He communicated through gestures and touch, including gentle pushing and pulling to physically direct someone to the object or activity he sought. Brian was an avid walker, often described as being in constant motion. Within just 13 weeks following his admission, at the age of 25, Brian was dead. During those 13 weeks, Brian was injured 57 different times. No one could explain his injuries on 18 occasions, even though during most of Brian's time at Kiley he had one staff member assigned on each shift to provide care and treatment only to him.

The true cause of Brian's death was never determined. The coroner was unwilling to rule that the cause of death was accidental but did not find sufficient evidence to rule Brian's death was a homicide either. What the medical examiner did find was that Brian died from blunt trauma to his abdomen that ruptured his intestine, causing massive infection. While the cause of the final trauma suffered by Brian may not be known, the events of the 13 weeks preceding Brian's death are grossly disturbing, revealing a picture of repeated trauma and wanton neglect.

The factors that eventually led to Brian's death are complex and interwoven. Brian's death was not attributable to a single action or omission, or the result of a single error or lapse in care. Brian's death resulted from a number of factors ranging from the lack of recognition of Brian's value as a human being by direct care staff, to doctors who viewed him as nothing more than a series of problems, to administrators who were not concerned with the well-being of those whose job it was to care for Brian. The discussion that follows breaks down each of these areas in detail as they relate to Brian's care.

II. October 30, 2002—The Day of Brian's Death

6:00 a.m.

During the midnight shift on October 30, an LPN arrived at Brian's unit for his morning medication and found that the staff member assigned to provide one-to-one care for Brian was missing. An incident report was completed for the staff member's neglect, and the various levels of the administrative and medical staff were notified. Brian's house manager asked Brian's doctor to examine him for any possible injuries that may have resulted from this lapse of care.

9:30 a.m.

The day shift began to notice that Brian was unusually lethargic. The young man they described as being in perpetual motion was still and quiet. Staff members documented that when Brian walked, he did so doubled over and that he had vomited. They reported later that he had vomited numerous times throughout the morning. In interviews afterwards, direct care staff stated that Brian shouldn't have been there, that he was too sick, and that he should have been in the hospital. A Kiley LPN performed a physical assessment but failed to recognize the severity of Brian's condition. The LPN did not request an assessment by an MD.

2:00 p.m.

Nearly eight hours passed between the time that the house manager asked Brian's doctor to perform an assessment and when the assessment was actually done. Despite such an extended lapse of time, the doctor performed only a perfunctory evaluation, determining that one of Brian's medications was the cause of his lethargy. She did not review the documentation kept by the staff that described him as walking doubled over and vomiting, nor did she inquire into any concerns that his attending direct care provider may have had. No abdominal assessment was conducted. Instead, the doctor ordered an antibiotic and assumed Brian's lethargy was due to an addition to his medication regimen. Subsequent to a State Department of Public Health investigation, the doctor who performed the exam stated that if she had been informed that Brian had been walking doubled over, she *maybe* would have done a more complete abdominal assessment. The doctor made no comment when it was presented to her that these findings were documented in Brian's record.

6:00 p.m.

Approximately four hours after the doctor examined Brian, he vomited a large amount of fluid and became unresponsive. Three direct care staff members were present in the house. The staff member assigned to Brian observed that he was not breathing and had "a very odd color." The direct care staff member then felt Brian's chest for a heartbeat but could not feel one; she then felt for a pulse in his neck and could not find one; she then attempted to find a pulse in his wrist, and again could not find one. Instead of administering CPR, as she should have done when she noted that Brian was not breathing and did not have a pulse, she called for help from the other direct care staff members present. Two other direct care staff members responded, and each attempted to find a pulse or some evidence that Brian was breathing. Each of them determined that Brian was not breathing and did not have a pulse. Instead of administering CPR as each of them had been trained and certified to do, they tried to revive Brian by "calling his name, moving him and continuing to try to get a pulse." Staff members also attempted to revive him by "rubbing his legs and arms and by propping him up in a chair." They provided ineffective and meaningless interventions until a supervisor arrived and began resuscitative efforts, but too much time may have already passed, and Brian was pronounced dead at a local hospital a short time later.

III. Abuse / Neglect

Providing care to people with disabilities in state-operated institutions is a multifaceted endeavor. Some aspects of care, such as the manner and practice of documentation, would seem less critical than such care as medical assessments and treatment, but typically there is a strong correlation of quality among all types and levels of care. Where a system allows inferior quality on one level, similar expectations are found in more critical areas. An examination of the way and manner in which Kiley administrators, doctors, nurses and staff comported themselves in terms of professionalism, competence and compassion reveals a fundamental attribute of the state institutional system that places all residents at risk.

The interrelation of unprofessional attitudes, administrative indifference, lack of competence and caregiver fatigue had ominous consequences for Brian. People under stress who do not possess the skills or are not given adequate support to effectively

cope and manage their own stress react in typical ways. Some staff members simply recognize the effect and remove themselves from the stressful situation. Others react to such stress more violently.

The number of injuries Brian suffered during the few months he resided at Kiley are staggering. The number of unexplained injuries, especially in light of the fact that Brian was assigned a staff member on a one-to-one basis, is incredible. It stands to reason that any person under such an intense level of supervision would never suffer an injury that could not be explained; yet in the span of 13 weeks, Brian had injuries that could not be explained on 18 occasions. On 12 of these occasions, no doctor conducted a medical exam to determine whether there were any signs indicating that Brian may have been abused.

Over the course of just 13 weeks, Brian suffered the following unexplained injuries:

7/31/02	8:40 a.m.	1-centimeter scratch to left cheek; redness to left ear.
8/5/02	9:55 a.m.	1-inch area of skin breakdown to right inner thigh.
8/11/02	7:20 a.m.	1-centimeter purple bruise to the “outer aspect of head.”
8/17/02	4:50 p.m.	Swelling noted under right eye; bruising and swelling noted to left jaw.
8/19/02	1:55 p.m.	Black and green bruise to outer right ear; light greenish bruise to left upper arm; purplish bruising to right ear.
8/19/02	11:40 p.m. ...	1/4-inch scratch to chest.
8/20/02	6:55 a.m.	Skin abrasion to left mid-thigh.
8/26/02	8:30 p.m.	Brownish discoloration to left forearm, 4 inches by 1 inch; 2 bruises to penile area, 2 inches in length.
8/27/02	2:40 p.m.	1-centimeter right shoulder scrape; 3-centimeter reddened area to right hip; 2-centimeter reddened area to neck; 1-centimeter reddened area to lower abdomen.
9/16/02	8:00 a.m.	1-centimeter-by-1-centimeter green/brownish bruise over corner of left eyelid and left cheekbone.
9/20/02	1:00 a.m.	Staff member observed Brian with blood “all over hands.”
9/24/02	3:15 p.m.	Swollen right hand with discoloration to knuckles.

10/10/02 ..... 7:30 p.m. ..... Large bruise to right upper leg; dime-sized bruises noted to each hip.

10/11/02..... 11:15 p.m. ... "Big red mark" to throat.

10/14/02 ..... 8:50 p.m. ..... 2-centimeter-by-1.5-centimeter bruise to upper left arm.

10/18/02 ..... 9:00 p.m. ..... 2-inch-by-1-inch red mark to chest and scrape to right knee.

10/23/02 ..... 10:00 p.m. ... Redness and bruising to outer left eye and below left eye.

10/29/02 ..... 7:00 a.m. ..... 1 1/2-inch scrape noted to upper right arm.

Indifference to Brian's pain and suffering was not limited to the doctors providing care at Kiley. The degree to which Kiley administrative staff members were willing to tolerate Brian's injuries is very troubling. On 12 separate occasions, administrative review of the incidents simply attributed the injuries to "life experience."

The progression of injuries that Brian suffered at Kiley is extraordinarily problematic when examined as a whole. While some of Brian's injuries were relatively minor accidents, other incidents were obviously more malevolent. Regardless, the incidents taken as a whole reveal that the treatment Brian received at Kiley, both in terms of the physical injuries suffered and the facility's response, demonstrates widespread indifference to his suffering.

On August 16, 2002, Brian sustained injuries to his face that one staff member described as looking as if Brian had been "beaten up." Shortly before this incident, due to the high number of unusual and unexplained injuries that Brian was suffering, direct care staff members were given an administrative directive requiring them to log at the beginning of their shift any new injuries that Brian had suffered. Interestingly, the staff member on duty at the time of the August 16 facial injuries failed to document any of the injuries. While the Office of the Inspector General substantiated a finding of neglect against this staff member, the administrative response to the finding of neglect, however, was to simply reassign the staff member to a different location to perform the same type of work despite their suspicions that he had beaten Brian. This staff member continues to work with people with disabilities. Shortly following the injury, Brian's parents visited and noted his swollen face. In response to Brian's parents' insistence that his facial injury be examined, Kiley doctors sent Brian to the emergency room for an

evaluation. A CAT scan was performed later that day that revealed that Brian had suffered a bilateral hematoma to the head, a condition in which a blood vessel between the brain and the skull ruptures.

Unfortunately, the August 16 incident was not an isolated event. Brian continued to suffer numerous injuries that were consistent with physical abuse. In late August of 2002, Brian was noted to have suffered bruising to the left side of his Adam's apple and to his pelvic area. A more thorough assessment conducted at a later time identified Brian's "pelvic bruising" as being bruises to his penis. The injury report related to this incident reveals that the doctor, who also happened to be the doctor who failed to identify Brian's life-threatening condition shortly before his death, declined to conduct an in-person assessment and chose merely to read the report, from which she determined that no treatment was required. On the day that Brian suffered these injuries, three different staff members documented their frustrations with working with Brian, with one staff member documenting that it had been an exhausting day for the staff. The administrative response to this incident and the staff's frustration was to hold a special habilitation team meeting, the result of which was to simply continue Brian's current plan of care.

Following the suspected physical assault in August, Brian's one-to-one supervision was expanded to a 24-hour-a-day basis, presumably under the assumption that such an intervention would make Brian safer. During the two months that followed this change, Brian suffered an injury or injuries on 15 occasions that staff members claimed they did not observe and could not explain, despite being within an arm's distance of Brian at all times.

In September of 2002, a staff member noted that a large area of hair was missing from the top of Brian's head. The staff member who documented the bald spot noted that it had not been there earlier during the shift. Again, despite staff requirements that staff members remain an arm's length from Brian at all times, there was no explanation as to how Brian lost a large patch of hair. It is interesting to note that of Brian's identified manifestations of his self-injurious behaviors, hair pulling was not included.

In October of 2002, incoming staff noticed marks across Brian's chest and an injury to his knee. The outgoing staff claimed that the injuries were old, but the incoming staff could find no record of such injuries. As was typical, follow-up to the potential abuse was little more than an RN's examination of Brian's injuries. Several days later, bruising was noted to the left side of Brian's neck, face and eye. There was no documentation that he had fallen or had sustained any injury on the previous shift, and

the staff member assigned to his care could offer no explanation as to the cause. Again, administrative response was limited to an RN assessment without an investigation into what may have caused the injuries.

On October 23 at 1:15 a.m., one week before his death, a nurse examined Brian for reasons that are not apparent from the record. The nurse's assessment noted that Brian was awake and on a one-to-one with staff. Brian was described as having good color and that his skin was warm and dry to the touch. There is no documentation with respect to bruising to his eyes or face. Later that same day, at 9 a.m., a second nursing assessment was conducted, and it was noted that Brian had suffered a bruise to his left eye and to the left side of his face. There is no documentation indicating that the direct care staff informed the RN of these injuries or offered any indication of how such injuries had occurred.

IV. Substandard Care and Treatment

a. Medical Staff Failures

The assessment that Brian was given just hours before his death was not an isolated incident of neglectful medical care, but rather the fatal culmination of a pattern of practice at Kiley in which some medical staff members appear to provide no more than perfunctory, substandard care. In fact, during the three months that Brian was a resident of Kiley, injury reports were completed on 57 occasions. On 38 of those occasions, or 67 percent of the time, Kiley doctors failed to perform an in-person assessment of his injuries. It is interesting to note that in attempting to determine the cause of Brian's death, Kiley medical staff identified a fall in late October that may have been a contributing factor. Like so many of the other incidents when Brian suffered an injury, Kiley doctors failed to conduct an in-person evaluation of this event following its occurrence.

The substandard care provided by the doctors and nurses had significant negative consequences for Brian because the kind of care they provided set the model of care for the rest of the treatment team. Such dismal role modeling results in a divestment in the individual's well-being and, in turn, allows all staff to disregard the expectations of quality service, which further dehumanizes the individual being served.

In September, the direct care staff documented that Brian had vomited three times, was coughing and had "green" nasal drainage. Brian's doctor performed a perfunctory evaluation and sent him to the ER to rule out a bowel obstruction. Despite documentation regarding Brian's cough and drainage, neither the Kiley nurses nor the Kiley doctor listened to his lungs or performed any type of respiratory assessment. Brian was admitted that day to the hospital with a diagnosis of pneumonia.

On the day Brian died, when the emergency call went out for assistance, rather than promptly responding, the doctor on duty called the operator to inquire into the nature of the emergency. The doctor on duty, who was on the grounds of the facility when staff called the emergency, arrived at Brian's residential building just minutes before the paramedics from the community responded to the call. While the paramedics established an airway by intubating Brian, the Kiley physician attempted to assist the paramedics by starting an IV but was unable to perform even this basic medical procedure. After intubating Brian, the paramedics later inserted the IV. An RN suggested in her documentation afterward that the difficulty starting the IV was attributable to the poor lighting in the house.

The nursing care Brian was provided at Kiley was no better. An injury report from August by an LPN says only "1 cm purple bruise to outer aspect." There is no additional description of the nature or location of the injury. The same doctor who examined Brian on the day of his death found that no medical intervention was necessary after reviewing this injury report. How such a determination was made with such limited information is astounding. No additional information was contained in Brian's records from which such a conclusion could competently be rendered. Another Kiley LPN documented that Brian was unsteady on his feet but later admitted to Department of Public Health Surveyors that she could not recall actually observing him walk.

In August 2002, Kiley treatment team leaders sought an orthopedic consult to address Brian's awkward gait and his difficulties ambulating. Knee immobilizers were ordered to provide greater stability. Two days after the immobilizers arrived, staff members documented that the braces were not being used because they had not been trained in their application. Several days later a direct care staff member requested assistance from Kiley nursing staff in the proper application of Brian's knee braces, but instead of offering assistance or instruction, the staff member was told by the RN to simply "read the instructions" and put the immobilizers on.

In September, a direct care provider noticed that Brian's hand was swollen and appeared injured. As was expected of her, she contacted the RN on duty. Instead of evaluating the extent of Brian's injury, the RN told her to tell the next shift because her

shift was almost over. The direct care staff member did as she was instructed, and upon examination by an RN on the next shift, the injury was deemed serious enough to send Brian to the emergency room for an evaluation.

Also in September, Brian exhibited challenging behaviors by repeatedly attempting to head-butt the direct care staff member. She contacted the nursing staff for assistance and guidance. A nurse observed the behavior for a brief period and then told the direct care staff member that all she could do was give Brian a Tylenol and then left the staff member to deal with the problem on her own.

b. Direct Care Staff Failures

The investigation conducted by various state agencies subsequent to Brian's death revealed a number of alarming admissions from staff members regarding the care that was routinely provided to Brian.

Brian wore a gait belt to assist the staff in steadying him, to prevent him from walking into people and furniture and to prevent falls. Though staff members were trained in the proper use of this device, many of them questioned whether this had been the cause of his death. Although numerous staff members, including a supervisor, thought that the belt could have caused the intestinal injury leading to Brian's death, only one staff member admitted to pulling too hard on the belt. Based upon the number of comments related to the belt, it is reasonable to conclude that more than one staff member either used or saw others use Brian's gait belt in an unsafe and improper manner. However, no staff member ever reported the improper use of the belt.

On September 1, the direct care staff documented that Brian had been "slobbering for two days." Putting the use of a word like "slobbering" aside, there is no indication that nursing or medical staff were made aware of the situation. As excessive salivation is a side effect for numerous medications, these observations should have been reported. Such lapses demonstrate that either the training that direct care staff received with respect to medication-related issues was woefully inadequate or that a culture of indifference pervaded the facility.

Brian was on a one-to-one supervision 24 hours a day when he died. Despite this, no staff member whose sole responsibility had been providing care to Brian was able or was willing to explain how he had been injured. The county coroner was unable to determine exactly what caused the perforation to Brian's intestine that led to his death, but a number of theories were offered. One possibility suggested that Brian had ruptured his intestinal lining from a fall. Documentation reveals that Brian fell on the 29th of October, the day before he died. The coroner's report indicates that the staff member

who was assigned to Brian's care that day was socializing on the phone at the time Brian fell. The next day Brian was again discovered unattended; just hours later, Brian was dead.

c. Administrative Failures

To simply castigate medical and direct care staff for the manner in which they provided services to Brian fails to recognize the critical leadership role that facility administrators have in setting expectations; maintaining effective systems of accountability; creating a culture that promotes and recognizes the value of individuals and their dignity; and ensuring the safety and well-being of those residing at the institution. Typically, such behaviors by staff do not appear without other influences. Certain factors must exist beforehand that serve to create an environment of indifference; these factors result from administrative modeling. The administrative indifference to the needs of the individuals being served is reflected in the low priority given to providing effective and quality training and support to direct care staff, the unwillingness to ensure that staff members were not overburdened, and the failure to respond proactively at the earliest signs of caregiver stress.

The effect of an act such as that of the RN who declined to examine a resident because her shift was almost over is greater than the mere delay of treatment. There is a message implicit in such actions, and that message is that people like Brian Kent simply are not important enough to be of concern.

Challenging individuals, such as Brian, require a concerted effort by both direct care staff and all levels of facility management. The respect given to individuals receiving services in state-operated facilities by administrators and managers is reflected in the level of support given to those staff members who provide daily direct care. In Brian's case, very little support of those staff members is revealed. The fact that Kiley administrators failed to equip their staff with the skills and resources necessary to effectively provide care for someone with needs such as Brian's is reflected in numerous examples taken from staff documentation that became apparent soon after Brian's admission to Kiley. Just two weeks into Brian's stay at Kiley, a staff member documented at the end of a shift, "Thank God, it's over."

The initial facility response to the stress inherent in providing care to Brian was to recommend that direct care staff members rotate one-to-one responsibilities every hour. The administration, however, never ensured that such rotation actually occurred, and consequently such sharing of responsibilities was rarely implemented. In fact, on the day of Brian's death, a direct care staff member was assigned to him for nearly 8

consecutive hours. The next direct care staff member was assigned to Brian's care from 2:30 until the time of his death four hours later. The failure to recognize the effect of caregiver stress had dire consequences for Brian. The growing hostility the staff felt toward Brian became more evident as the tone of staff documentation became more hostile.

At the same time as the staff's growing and festering hostility, the number of people who were willing to share in taking responsibility for Brian's care dwindled. A direct care staff member who worked in a nearby Kiley housing unit stated that he never volunteered to work at Brian's location because it was "too stressful." Another staff member stated that working with Brian was "very stressful" and lamented that he often was required to work with Brian because he had low seniority and was frequently mandated to work overtime. Other staff members had simply decided to work elsewhere due to the frequency at which they were required to work overtime under stressful conditions.

The levels of staff frustration elevated while the Kiley administrators continued to disregard the working conditions of direct care staff. At the end of a shift on August 15, a staff member documented that "even changing off every two hours is hard on staff," and on August 25, one described working with Brian as "an ordeal." Not surprisingly, as the administrators continued to ignore the blatant warning signs of stress among the staff, the number of unexplained injuries Brian suffered continued to rise.

In mid-August, Kiley resident advisers developed a list of alternative strategies to assist the direct care staff with Brian's behaviors, but it soon became clear that such interventions were ineffective and did not ameliorate Brian's difficult behaviors. In fact, by the time of Brian's death at the end of October, no significant changes had been made to Brian's plan of care despite nearly daily documentation for almost two months indicating that the proposed plan was ineffective and inappropriate. Brian's plan of care provided the mere appearance of intervention but in reality did not provide any true or workable strategies.

By September, Brian had begun to become more aggressive. He would strike at staff members, hitting them in the arms, stomach and groin. Despite the increasing violence, staff members were given no direction as to the potential cause of his outbursts nor were they offered alternative strategies to minimize such incidents. Brian's behaviors worsened to the point that he began head-butting staff members, and, despite their protestations, they found the only viable alternative at their disposal was to don helmets to protect themselves from injury.

Kiley staff did not consider whether any aspect of Brian's behavior was related to an attempt to communicate through gestures or physical prompts or whether the increased level of aggression resulted from staff failure to recognize those communication efforts. Although Brian's parents visited regularly, Kiley staff did not advise them of the extent of the aggression or seek assistance from the Kents in order to develop alternative strategies to address the increased level of aggression.

After more than a month of significant negative behaviors, the concerns raised by the direct care staff still had not been appropriately addressed by Kiley psychiatrists. On October 19, staff documented that Brian was having difficulties throughout the night. Brian's record states, "[Brian] slept about 2 [minutes]. Now he's up again." Two hours later, the same staff member wrote, "Brian is at this time a very live wire...Keeps getting out of bed, still awake with a wild look on his face..."

By late October, Brian's sleeping difficulties, which first had become apparent as early as July, still had not been addressed, nor had the Kiley administrators sufficiently provided the means to reduce the stress levels of the direct care staff. When administrators treat direct care staff members like disposable commodities, in turn, the direct care staff members then treat individuals like Brian in a similar manner. On the 27th of October, Brian was awake for the incoming midnight shift; the staff reported that he had spent the evening walking and pushing staff members. Direct care providers documented that the recommended behavioral plans for Brian "[are] no solution at all." The level of staff stress is evident in such documentation as "Now at this time he's up" followed by three exclamation points. Just three days later Brian would be dead.

An investigation conducted by Public Health subsequent to Brian's death cited Kiley administrators for their failure to provide direct care staff with the skills and competencies necessary to provide care for Brian. Such a finding should come as no surprise. The more important question, however, is why Brian and other similarly vulnerable people continue to be subjected to such substandard treatment.

V. Substandard Medical, Nursing and Direct Care: An Ongoing Problem Across Illinois' State-Operated Developmental Disability Institutions

Tragically, similar events, omissions and errors have been documented at other state-operated developmental disability facilities by the Abuse Investigation Unit and through state agency investigations. The responsibility for such lapses in care may

fall solidly upon the administration of developmental centers for failing to provide the appropriate training and for allowing such transgressions to continue, but even properly trained direct care staff members have been noted to disregard those expectations placed upon them. The following deaths illustrate and are representative of the same kind of abhorrent care that led to Brian Kent's death and illustrate the depth of the substandard care routinely tolerated within the state-operated developmental disability centers.

Deaths in State-Operated Developmental Disability Institutions:

In April 2003, an individual died following the staff's failure to follow physician orders to notify the doctor of increased aggression and to monitor vital signs. Several months prior to the individual's death, in response to an abnormal electrocardiogram and a planned medication reduction, the individual's interdisciplinary team met to develop a plan to address the abnormal heart test and the potential side effects that the medication reduction plan could have on his heart condition, which included notifying the physician if the individual displayed increased aggression and monitoring his vital signs daily. The nursing staff did not contact the physician following 30 instances of increased aggression and failed to monitor his vital signs on a daily basis. On the day the individual died, for nine hours he displayed numerous signs of distress, including aggression, yelling, picking at his buttocks, foaming at the mouth, grabbing at staff members, banging his head on the wall and breathing laboriously. Staff addressed these behaviors in several ways—restraining the individual, using emergency medications and eventually putting him to bed, where he remained restless, moaning, and with "clammy"-feeling skin. Fifteen minutes after a final dose of emergency medication, the individual became unresponsive and was transported to a hospital, where he was pronounced dead.

In April 2004, an individual choked on a meatball approximately two inches in diameter. The individual, who had a history of pica (the ingestion of inedible objects) behavior was on one-to-one staff supervision, requiring a staff member to "maintain visual observation within one arm's length" at all times. In response to the choking, the unit nurse called a "Code Blue." The physician on that unit, who was only 30 feet away in his office, stated that his pager malfunctioned and he did not receive the Code Blue page. Had he received the code, the physician indicated that he would have used the facility's laryngoscope and, if that was not successful, could have done a different emergency procedure to create another airway. The staff's attempts to dislodge the meatball were unsuccessful. When the paramedics arrived on the scene, they utilized

a laryngoscope and were able to remove the meatball. However, by that time, the individual was already unresponsive and had no pulse. At the time of the death, the facility was aware that its Code Blue system did not function properly.

In March 2005, an individual died from respiratory failure and an upper gastrointestinal bleed. The individual was diagnosed with constipation, chronic airway obstruction, bronchospasm and gastroesophogeal disease, and had recently been treated for pneumonia, which required ongoing medical treatment by the staff. The individual was also being monitored for constipation. The day the individual died, a 6:00 a.m. nursing note indicated that he had a low-grade fever, a blood pressure of 130/78, a pulse of 70 and respirations of 16. No oxygen saturation level was checked, and the individual 's name was placed on the log for him to be seen by a doctor for assessment that morning. A 9:00 a.m. nursing note indicated that his vital signs were taken and oxygen saturation level was tested. A corresponding physician note included an assessment of the individual's constipation and noted that his abdomen was distended. The physician recommended a surgical consult for the constipation. At 10:00 a.m., a nurse tested his blood pressure and temperature. No further assessments of his distended abdomen, oxygen saturation level or vital signs were conducted after 10:00 a.m. At 12:45 p.m., a nurse checked on the individual but simply wrote that there were no signs or symptoms of discomfort. At 5:45 p.m., the individual had an episode of respiratory distress, but then his color was reported to have returned to normal and there was no further nursing follow-up. At 7:00 p.m., he was observed lying on top of the bed covers moaning, and did not respond when asked if he was okay. At 8 p.m., the individual had another respiratory crisis and was transferred to a local hospital and then airlifted to a larger hospital in another state, where he died the next day.

In March 2005, an individual died following the staff's failure to ensure an ongoing system to assess an individual's vital signs and respiratory status and to ensure immediate transport to a hospital when medical emergencies occur. In late February, the individual was taken to a hospital to evaluate the status of her pneumonia, diagnosed the month before, which the hospital determined was still unresolved. Several days later, the individual returned to the facility, and staff members were instructed to monitor the individual for signs of nausea/vomiting and signs of infection but were not instructed to monitor for the effects of the unresolved pneumonia. Later that same day, progress notes documented normal vital signs and even and unlabored respirations. At midnight, the special nursing care progress notes indicated that the staff member was unable to listen to the individual's lungs because she would not remain still. The next day at 4:00 a.m., a staff member noted that the individual's skin was damp with perspiration and

she was restless. A staff member took the individual's temperature and blood pressure and gave her Tylenol to address a fever. There was no further documentation of the individual's vital signs for another 10 hours. At 5:30 p.m., a nurse documented that there were no signs or symptoms of distress. However, the nurse was unable to hear lung sounds because the individual was so restless. There was no further documentation of any assessment of the individual's condition until 9:00 p.m. when a staff member found her in bed flailing her arms and legs and cyanotic (blue). The staff member called a Code Blue, and approximately 25 minutes later, she was transferred to the hospital, where she died two days later.

In September 2005, a 36-year-old man died shortly after a direct care staff member documented and notified nursing and medical staff that he was in pain, was moaning and was refusing to eat. The following morning an assessment by the doctor was conducted that consisted in its entirety of vital signs and the words "Alert, no c/o [complaint of] pain" and "monitor." No abdominal assessment was performed, no findings related to bowel sounds were noted, nor was any assessment done regarding his ability to ingest food. Later that day, an RN conducted a follow-up assessment and found him to be sluggish, pale and in acute distress. The individual was sent to the emergency room and died a short time afterward. The cause of his death was determined to be peritonitis, the same cause of death as Brian Kent's.

In October 2005, a 65-year-old man died following a particularly egregious series of nursing assessments. Shortly before his death, a direct care staff member documented at least seven loose-stool episodes within a three-hour span of time. Nursing staff were informed and an assessment was conducted. The nursing assessment, while noting an additional loose stool during the assessment, was largely unremarkable. The nurse noted tremors but found all vitals to be normal. No assessments were performed as to hydration status. No follow-up RN assessment was conducted until nearly 12 hours later. At that time, the RN documented that this man was in "no apparent distress." Vitals were taken and all were found to be normal. Approximately 20 minutes after this RN assessment, the doctor's assessment revealed a much different scenario. The doctor found that he in fact had a temperature of nearly 104, his blood pressure was falling, his abdomen was distended and he exhibited signs of severe dehydration. The man was immediately sent to a local emergency room, was admitted to the hospital and died a short time thereafter.

In November of 2005, a 61-year-old man choked on a mouthful of food while eating dinner and fell to the floor. A swallow study conducted five months previously resulted in a dietary plan requiring that the individual receive finely chopped meats and bread

soaked in liquids. In spite of a dietary and nutritional assessment completed eight months before the choking incident that identified the individual's tendency to stuff his mouth full of food and eat at a very fast pace, the facility had not developed an eating pacing program to address these issues. Staff efforts to dislodge the food by abdominal thrusts and suctioning were not successful. The individual remained cyanotic without visible signs of circulation or breathing. The individual was transferred to a hospital, where he died one week later.

In February of 2006, a 71-year-old man developed seven pressure ulcers, including a stage-four ulcer, on his buttocks. In addition to the development of these decubitus ulcers (bedsores), doctors had to give strict orders for direct care staff to provide good perineal care because of the skin breakdown he was experiencing from being left sitting in his own urine for extended periods of time. Despite the ongoing problem related to the pressure sores, no nursing care plans were developed to address the issue, MD orders were not followed and the facility failed to implement a plan of care that would effectively address his needs until it was too late. The man died just four days after he had been transferred to a different facility.

In April 2006, a 55-year-old man was noted to be unresponsive while sitting in his wheelchair. The direct care staff member in attendance discovered that he was not breathing and that he did not have a palpable pulse, but instead of promptly initiating CPR as trained and certified, the direct care staff member merely called for help and let the responding nurse initiate CPR. Unfortunately, this failure was hardly the first medical lapse in the care that was provided to this man. The previous month orders were given to monitor vital signs every shift for 72 hours. The record contained no indication that this monitoring was ever performed. Additionally, because this man used a wheelchair and was at risk for developing decubiti (bedsores), doctors ordered that staff change his position in his chair every two hours. On the evening of his death, documentation reveals that he sat in his chair without a change in position for nearly five hours before a staff member discovered that he was no longer breathing. EMTs responding to the scene noted that rigor mortis had already begun to set in.

In April 2006, a 70-year-old man died after months of documentation by the direct care staff that he appeared to be in a great deal of pain. Despite this ongoing documentation of pain, no assessments were conducted as to the effectiveness of pain management. Shortly before his death, orders for strict monitoring of the amounts of food and liquid along with the amounts excreted went ignored. The attending doctor

performed an assessment at 1:00 p.m. on the day of his death from which he stated that the individual was clinically stable. Seven hours later he was found with no pulse and no respirations.

In June of 2006, a 56-year-old man with insulin-dependent diabetes died following months of poorly controlled blood sugar levels and inadequate nursing care related to such levels. The staff repeatedly documented blood sugars higher than 400 (with normal being in the range of 80 to 120) but failed to notify a doctor or request follow-up by the RN. On the evening of this individual's death, a blood sugar of 402 was noted. No insulin was given, nor was a doctor notified.

In February 2007, an individual with significant heart disease who required anti-anxiety medication before undergoing medical procedures to ensure that she would remain calm died following a routine medical procedure. At the time of the death, staff members were aware that the medication was required and that when given, the individual could calmly undergo various procedures, including dental procedures, mammograms and pap smears. Prior to an unscheduled pap smear, the direct care staff members 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.

VI. Conclusions and Recommendations

This report dramatically illustrates the tragic loss of individual lives resulting from a myriad of failures within Illinois' system of state-run developmental disability institutions, a system constructed more than 100 years ago in an effort to provide support and services to people with disabilities. The report also illustrates the depth of the culture that has evolved within Illinois' system of state-run developmental disability institutions and that continues to be endemic to that system. It is a culture that dehumanizes individuals with disabilities and ignores their fundamental rights to live safely and to be afforded quality care. It is also a culture that has repeatedly shown itself as not amenable to change. Large congregate settings, by their very nature, marginalize people with

disabilities and foster abuse and neglect. So long as Illinois continues to protect its archaic system of state-operated institutions, the individuals who remain in that system will continue to be at substantial risk of injury and death and the kinds of tragedies revealed by this report will continue.

In spite of the substantial resources that Illinois has poured into troubled state-operated developmental disability institutions in an attempt to fix egregious conditions on an emergency basis, positive sustainable change has not resulted. The State cannot continue to waste public money when the average cost per person in a state-run institution is several times more than the cost of serving the same person in the community. Rather than wasting the State's limited resources fixing a system that is routinely recognized as contrary to accepted standards of care and best practices, such funds should be used to identify and implement the steps necessary to end Illinois' overreliance on large state-run institutions.

Illinois must address its overreliance on large state-run institutions and develop and implement a plan to close the most problematic state-run developmental disability institutions, while at the same time taking the steps necessary to ensure the safety of the individuals residing in the remaining state-operated institutions by remedying the problems that led to the deaths described in this report. At a minimum the State's actions should require:

Independent Interdisciplinary Monitors

- Develop independent interdisciplinary teams of monitors, approved by the Illinois Departments of Public Health and Human Services, to ensure on a routine basis the safety and well-being of the individuals residing at each state-operated developmental disability institution.
- Require the monitoring teams to produce quarterly reports of their observations and release those reports to Equip for Equality and the Departments to develop and implement the steps necessary to ensure that individuals are safe and receive quality services and medical care.

Independent Medical Experts

- Develop an independent team of medical experts from the private sector, including forensic pathologists, doctors and nurses, to examine all deaths at state-operated developmental disability institutions, render findings regarding adequacy of medical care and treatment, and release those findings to the Departments of Public Health and Human Services and Equip for Equality to prevent further tragedies. Information regarding the findings, which maintains the confidentiality of the individual involved where appropriate, will be made publicly available by the Departments.

Enhanced State Investigatory Agency Capacity

- Increase funding for state agencies responsible for investigating allegations of abuse, neglect or quality of care, to ensure timely and thorough investigations.

Statutory and Regulatory Changes

- Expand the definition of abuse of individuals with disabilities to include inadequate medical care that, regardless of the final cause of death, compromises an individual's health or leads to serious medical consequences followed by the individual's death.
- Expand the definition of neglect to include the failure to follow medical and personal care protocols, such as dietary restrictions, regardless of whether that failure causes injury.
- Require the Departments of Human Services and Public Health, along with the facility administrator and medical director, to develop a plan of prevention following the death of any individual at a state-run developmental disability institution to ensure that similar deaths do not occur.
- Mandate the provision of attorney fees and damages to ensure access to legal advocacy for the families of those who have died at state-operated developmental disability facilities.

Expand the Capacity of the Community-Based System of Services

- Provide additional funding to address the significant shortage of resources currently made available to the community-based service delivery system so that the wants and needs of individuals with disabilities who currently receive services through that system, and those individuals who seek to receive services through that system, can be met.
- Ensure that individuals with disabilities and their guardians and families receive sufficient information to understand their rights and to allow for informed decision making regarding the provision of services that can meet the individual's wants and needs.
- Provide sufficiently enhanced funding to allow community service providers to meet the wants and needs of individuals served in the community, including the needs of people with the most significant challenges.