



**A Collection of Case Studies Provoking Reflection,
Discussion, and Action**

Volume II

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From the Chair—

In 1992, Mildred Thomas, a resident of a group home in western New York State, died a preventable death. Consistent with its mandate, the Commission on Quality of Care for the Mentally Disabled conducted an investigation and issued a report of findings and recommendations to the agency; and the agency implemented a plan of corrective actions to reduce the likelihood of a similar occurrence.

Eighteen months later, at a group home operated by a different agency in southern New York, Mary Rose died. The Commission's investigation revealed she died under circumstances very similar to Mildred's. More importantly, the investigation suggested to the Commission that had Mildred's case and the corrective actions taken by her agency following her death been known to Mary Rose's service provider, perhaps Mary Rose's death could have been avoided.

This realization was the impetus for *Could This Happen In Your Program?* Historically, whenever the Commission investigated a matter — a consumer complaint, an allegation of abuse, or an unusual death — it shared its findings and recommendations with the involved agency, a practice which continues to this day. The deaths of Mildred and Mary Rose, however, suggested that there was a need to broadcast the lessons learned by one facility as a result of a serious, preventable, even fatal event, to as many facilities as possible to prevent similar future occurrences. *Could This Happen In Your Program?* is the Commission's attempt to meet that need.

Could This Happen In Your Program? is a series of case studies drawn from the Commission's investigation files. Protecting the identity of agencies and individuals, it presents real-life situations which could have been avoided or managed differently. Each case study in this continuing series poses questions or discussion points which can guide agencies in a critical examination of their own operations and actions which may be needed to ensure that the individuals they serve receive appropriate care.

Since its introduction in 1994, the series has undergone a number of "face lifts," largely in response to readers' comments. The first case studies were produced on multicolored paper in tri-fold, brochure format. Today, they are produced in a color and format which allows for easier reproduction so that agencies can disseminate them as widely as possible. In 1997, we reproduced the 28 previously published studies in the newest format in a single compendium, which allows easy reproduction and insertion in three-ring or other binders.

While the "face" of *Could This Happen In Your Program?* has changed, its "soul" remains the same. It provides an opportunity for all staff of all agencies to engage in critical self-examination, answering the questions "Could this happen here?" and "What must we do to ensure it doesn't?"

I would appreciate your comments on the five cases in this most recent installment of *Could This Happen In Your Program?* as well as subjects you would like to see addressed in future issues.

Gary O'Brien

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**NYS COMMISSION
ON QUALITY OF CARE
FOR THE MENTALLY DISABLED**

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*Note: The first volume of **Could This Happen In Your Program?**, which contains 28 case studies, can be ordered from the Commission for a fee of \$10. Requests for copies, along with a check or money order made out to the Commission on Quality of Care, should be sent to **Anne Harrienger** at the following address:*

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In the Matter of James Quigley*

Supervision and Adaptive Equipment

Case #29

The Event

On Friday evening when Ms. Sullivan finished changing one of the 11 profoundly disabled children living in the group home where she worked, she returned to the living room where she had been watching four children. Four other staff were in the dining room assisting the other children with their evening meal.

Upon re-entering the living room, Ms. Sullivan noticed that something was very wrong with James Quigley, a 14-year-old resident who required the use of a supine stander.¹ His face was pale, his lips blue. Another client was sitting on the floor at the foot of the stander playing with its velcro straps which, when fastened, would secure James' feet and legs in the stander. The straps, however, had come undone, and James' feet had slipped off the stander's platform. James was being held in the device by an upper torso V-shaped harness which had compressed against his neck.

Ms. Sullivan screamed for help as she attempted to lift James and remove the harness. Responding staff assisted her, initiated CPR and called 911 for emergency medical assistance.

James was transported to a local hospital, then air-lifted to a major medical center. He had suffered severe anoxia and neurological tests indicated that he was brain dead. With his parents' permission, James was removed from life support and pronounced dead. Upon autopsy, death was attributed to accidental asphyxia "due to neck compression by stander strap."

Background

James Quigley was born an apparently healthy baby, the product of a full-term pregnancy and uncomplicated delivery. For the first six months of his life, he was a contented infant and seemed to develop normally. Breast fed, his appetite was good, he smiled, grasped for toys and reached developmental milestones within normal limits.

However, at six months of age, James experienced his first seizure. His parents sought immediate medical attention and he was transferred to a children's hospital for further tests. James was diagnosed as having cerebral palsy, and a seizure disorder. Further developmental milestones were profoundly delayed.

When he was four years old, James' parents enrolled him in a day school for special children. He was non-ambulatory, and unable to sit or stand unassisted. He was also nonverbal and suffered from spastic quadriplegia. He expressed needs and pleasures through facial expressions and vocalizations. Over the years, he tested in the profound range of mental retardation.

* All names are pseudonyms.

¹ The supine stander is a piece of adaptive equipment which enables its user, who cannot independently stand, to be supported in an upright, standing position. The individual is strapped, in a supine position, to a back board, with his feet and legs, waist and upper torso secured to the board with straps. The board is then cranked/tilted to an upright position. A tray can be attached to the stander in front of the individual so he can rest his arms or play with toys on it.

At seven years of age, James was accepted into a group home serving 10 other children with serious developmental disabilities. His parents remained very active in his care while group home staff complemented the professional services offered by his school program. Services included speech, occupational and physical therapies as well as assistance in daily living skills.

In the home, James required certain protective and/or adaptive equipment. For example, due to ongoing seizures, James needed to wear a helmet and to have bed rails at night to prevent injury in case of a seizure. He also required the use of the supine stander.

James was to be placed in the stander each evening for 45 minutes to promote muscle development and his ability to bear weight.

James lived in his group home for seven years without major incident until the evening when Ms. Sullivan found him hanging from the straps of his stander in the living room.

Investigations

James' fatal accident prompted both police and administrative investigations. While the police closed their investigation finding no criminality, administrative investigations revealed that James' death was entirely preventable, and due to lapses in supervision. A problem with adaptive equipment modifications was also discovered.

On the evening of James' accident, five staff, including the shift supervisor, were on duty. As on other nights, the 11 residents were scheduled to eat dinner in two shifts, thus enabling staff to give the children maximal attention during this important skill-building and pleasurable activity. While one group of children would eat in the dining room with four staff, another group would wait its turn for dinner in the living room, watching TV or listening to music with the fifth staff member. An unwritten rule of the home was that the staff member assigned to "sit-out" duty — that is, to sit with the children awaiting dinner in the living room — would not leave the children unattended.

Additionally, the home had written guidelines on the level of supervision each child required. Some kids, like James, had to be within staff's line-of-sight at all times. Others had to be visually checked by staff at certain intervals, e.g., every ten minutes.

When Ms. Sullivan reported to work that fateful Friday evening, she was assigned "sit-out" duty for the first seating of the evening meal.

Shortly after 5 p.m., dinner was served. Seven of the children and four staff went to the dining room. While staff assisted the children with their evening meal, Ms. Sullivan remained in the living room with four children. Two of the four children — James, who had been placed in his supine stander just before dinner-time as per his habilitation plan, and Donna — were to be within staff's sight at all times.

At approximately 5:30 p.m., the shift supervisor approached Ms. Sullivan in the living room. She reported that one of the kids eating dinner had had a toileting accident, and that his mother was coming shortly to visit. The supervisor asked Ms. Sullivan to take the child to his room to change him, in anticipation of his mother's visit.

Ms. Sullivan questioned, "Right now?" knowing that she was assigned to "sit-out" duty with the four children in the living room. The supervisor responded affirmatively and indicated that the first dinner shift was almost done, that the four children in the living room would soon be brought to the dining room and that, in the interim, she (the supervisor) would keep an eye on them.

Following the supervisor's instructions, Ms. Sullivan escorted the child to his room where she cleaned him and changed his clothes, tasks which took less than 10 minutes by her estimation.

She then escorted the child back towards the living and dining room area, stopping briefly to drop his soiled clothes in the laundry room.

When Ms. Sullivan was changing the young man, the shift supervisor left the living room, and the four clients there, to return to the dining room across the hall and assist with the meal, which was now ending. At one point she went back to the living room doorway to check on the four clients; all was well, she thought, and she returned to the dining room. As the supervisor reported, approximately three minutes later, she heard screams.

The screams were Ms. Sullivan's. Upon re-entering the living room where she had been stationed, Ms. Sullivan found James hanging by his neck in the stander; Donna, the other child requiring constant observation, was sitting on the floor in front of James, playing with the velcro straps which should have held his feet and legs supported in the stander.

Based on the investigations, it was concluded that in all probability, while the children were left unattended in the living room, Donna — who was fond of playing with the supine stander — unfastened its velcro leg straps, and unintentionally caused the fatal accident.

It was also concluded that the shift supervisor violated clear, written guidelines concerning line-of-sight supervision for certain children when she instructed Ms. Quigley to change the soiled child and left James and Donna unattended in the living room. The supervisor was terminated from service.

Two other problems with supervision were found. Although it was the unwritten rule of the house that the person assigned to "sit-out" duty in the living room would not leave that station, staff reported that this unwritten rule was sometimes violated when other duties demanded their attention. Similar breaches of the formal written line-of-sight supervision instructions for particular children occurred intermittently because staff were assigned too many different children to keep in sight at all times ... How does one keep two boys and one girl in sight at all times when one of them has a toileting accident and needs to be bathed and changed?

It was also found that the manufacturer's instructions for the supine stander's use were violated in two regards. First, the stander manufacturer recommended that use of the stander requires adult supervision "at all times," which clearly didn't occur in this case.

Secondly, the manufacturer recommended that any modifications to the stander be made under the direct supervision of a qualified, licensed professional, such as a physician or physical therapist, who should then test the modifications on the individual and certify in writing that they are safe and satisfactory.

Approximately two years before his death, James' stander was modified; the upper torso H-shaped harness was changed to a V-shaped harness, in order to hold his upper body and head in an upright position. Although designed by the agency's PT/OT Department, the agency never secured written certification that the modification was tested and found to be safe and satisfactory.

Lessons Learned

Following investigation of James' untimely and preventable death, the agency instituted a number of disciplinary and corrective actions. The lessons it learned present questions for others to probe:

- Are expectations for staff supervision of clients clear, are they realistic, and are they do-able?
- Are there "unwritten" rules for supervision which should be formalized? By the same token, are there deviations from written rules on supervision due to everyday realities, which suggest the need to revisit and refine formal supervision expectations?

- What is a direct care worker expected to do when a supervisor requests that s/he violate a standard of care ... even if the request makes sense on a certain level; for example, not supervising some clients in order to change another client who's had a toileting accident?
- Are staff well-trained and sensitized to the dangers of adaptive equipment, as well as their benefit, and instructions for proper use?
- Does the agency ensure the use and modification of adaptive equipment is in accord with the manufacturer's instructions?

Agency Self Assessment

1. Could this happen in our program? Yes No
2. What lessons, if any, are applicable to our program?

3. Are there steps we should take to reduce the risk of similar problems in our programs?

4. Person/Department responsible for follow-up.

5. Expected date of completion of actions identified in question number 3.

Additional Notes

In the Matter of Mindy Paulov*

Medical Recommendations Go Unheeded Case #30

Background

Mindy Paulov was 48 years old when she died after six months of psychiatric treatment at a down-state hospital.

Ms. Paulov's psychiatric difficulties first manifested themselves when she was 19 years old and away at college. She dropped out of school, returned to her parents' home and began outpatient therapy with a private psychiatrist.

While in therapy, Ms. Paulov returned to school, locally, and she earned her bachelor's degree. Following graduation, she worked as a researcher.

In her late 20s, however, Ms. Paulov experienced a severe exacerbation of her psychiatric symptoms which necessitated her first psychiatric hospitalization. She was diagnosed as having schizophrenia.

Following that hospitalization, Ms. Paulov worked intermittently while receiving outpatient services. However, in time she would discontinue outpatient services, decompensate and require hospitalization for stabilization — a pattern which was repeated a number of times over the next 15 years. She was diagnosed as suffering from chronic undifferentiated schizophrenia. Medical work-ups also indicated she was suffering from hyperthyroidism.

By her mid-40s, Ms. Paulov no longer worked in the competitive market. Tired of her experiences with psychiatric day programs, Ms. Paulov refused to go. She preferred to stay at home and receive clinic services on a periodic basis. Her compliance with clinic appointments for evaluations, medications, etc., was sporadic, at best.

Ms. Paulov's parents, now elderly and retired in Florida, supported her financially and checked on her well-being through frequent visits to New York and regular telephone contact.

Final Hospitalization

In the summer of her 48th year, Ms. Paulov's parents became concerned when a number of their attempts to contact her by phone were unsuccessful; no one answered the phone. When her parents eventually did reach Ms. Paulov, she seemed confused, her speech was rambling and disorganized. The Paulovs contacted social services officials in New York who visited Ms. Paulov: her apartment was a mess, her personal hygiene poor, she was emaciated, and it appeared that she was unable to care for herself. She was admitted to a psychiatric unit of a local hospital.

Upon admission, Ms. Paulov was floridly psychotic, anxious and agitated. She denied suicidal or homicidal ideation, but was unable to give a reliable history. Through family contacts and consultations with past providers, the hospital was able to establish Ms. Paulov's psychiatric and medical history, including hyperthyroidism. Initial blood chemistries revealed elevated, although not dangerous, calcium levels consistent with hyperthyroidism. (Ms. Paulov's calcium level was 11.9; the norm is between 8.7 and 10.7 mg/DL.) The treatment plan, in part, called for stabilizing

*All names are pseudonyms.

Ms. Paulov's psychiatric condition with medications and medical work-ups to assess her thyroid condition. It was planned that Ms. Paulov would be placed in a supervised residence, once stable.

During the first three months of hospitalization, Ms. Paulov was tried on a variety of psychotropic medications. Her mental status remained unchanged: she continued to be psychotic, agitated and disorganized.

Psychiatric service staff proposed the possibility of ECT, to which Ms. Paulov objected. Convinced of its need, the hospital sought a court order permitting the administration of ECT over the patient's objections.

During the same period, Ms. Paulov's blood chemistries remained abnormal, although not dangerously so, particularly her calcium level. Ultrasound and MRI tests suggested that Ms. Paulov had a right parathyroid adenoma (i.e., benign tumor). As it was felt that Ms. Paulov's tumor and hypercalcemia might be contributing to her mental status and poor response to medications, the medical specialists recommended surgery (parathyroidectomy). The recommendation was not acted on, and the psychiatry service offered no rationale as to why it wasn't.

During the fall, court permission for ECT was received. Over the next nearly two months, Ms. Paulov underwent 22 ECT sessions. Her mental status, at the end, was still unchanged. In the interim, blood chemistries indicated that Ms. Paulov remained hypercalcemic.

In mid-November, endocrinologists again recommended surgery to correct Ms. Paulov's parathyroid condition and hypercalcemia. The recommendation was rejected as psychiatrists felt that Ms. Paulov lacked the capacity to consent to the procedure.

Since Ms. Paulov remained extremely psychotic and refractory to treatment, in December the psychiatry service began making referrals for her long-term care in a state psychiatric center.

Shortly after Christmas, however, as transfer arrangements were being worked out, Ms. Paulov was noted to be lethargic and hypotensive. Blood chemistries indicated that her electrolyte, cardiac and calcium levels were significantly abnormal. Her calcium level was dangerously high at 22.3.

Ms. Paulov was transferred from psychiatry to a medical service and then eventually to the hospital's ICU. Her diagnosis was malignant hypercalcemia secondary to hyperthyroidism.

Over the next 48 hours, Ms. Paulov's condition quickly deteriorated. She became dehydrated and experienced respiratory distress and renal failure. A parathyroidectomy was recommended, once her medical condition could be stabilized; however, despite aggressive care, she suffered cardiopulmonary arrest and expired. Her death was attributed to hypercalcemia.

Discussion

With the benefit of 20/20 hindsight, retrospective reviews of the circumstances of Ms. Paulov's death resulted in the conclusion that her death was entirely preventable. She died as a result of a hypercalcemic crisis resulting from her parathyroid adenoma; at least twice during her six month psychiatric hospitalization, medical specialists recommended surgery to correct the underlying parathyroid condition. In fact, it was felt that this underlying medical condition may have been contributing to Ms. Paulov's poor response to psychotropic medications and her intractable psychiatric difficulties.

Had the surgery been performed, as medical specialists had twice recommended before her hypercalcemia crisis, Ms. Paulov would probably be alive today. But it wasn't.

Why wasn't it?

The retrospective reviews tended to indicate that psychiatrists in charge of Ms. Paulov's care, while focusing on stabilizing her mental status, did not fully appreciate her medical condition. Medical specialists called in to assess Ms. Paulov's hyperthyroid condition recommended surgery; it was even speculated that her unremitting psychotic state was the result of the underlying medical condition.

The psychiatric service never disputed the recommendations of the medical specialists. When surgery was first recommended, psychiatry offered no rationale as to why it should not proceed. When surgery was again recommended months later, psychiatry simply noted that Ms. Paulov lacked the capacity to consent to the recommended medical/surgical intervention. However, at the same time, in order to treat her psychiatrically, the psychiatric service sought judicial consent to administer ECT on Ms. Paulov.

In short, while psychiatrists focused on Ms. Paulov's mental health and pulled out all the stops, including securing a court order, to provide psychiatric interventions, their myopic vision clouded a view of her overall health ... they did not pursue court orders for recommended medical interventions. In the absence of recommended medical/surgical interventions, Ms. Paulov died.

Lessons Learned

The circumstances of Ms. Paulov's death offer service providers several critical questions to reflect upon as they review and, if necessary, fine-tune their operations:

- In the face of presenting psychiatric symptomatology, are underlying medical conditions considered and ruled in or out?
- If medical specialists identify medical conditions and offer recommendations for treatment, are these recommendations given equal weight as recommendations for psychiatric care? Are they accepted or rejected after careful clinical consideration and discussion and is the rationale for the ultimate clinical decision documented?
- If capacity to consent is perceived to be the sole obstacle to rendering recommended medical/surgical care, are there mechanisms in place to evaluate and enhance the individual's ability to consent, and to secure surrogate consent (from the court or other parties) if the patient lacks the capacity and the recommended medical procedure is deemed necessary?
- Are all staff aware of the facility's policies, procedures and expectations concerning securing medical consultations, making determinations (and documenting such) on recommendations for medical interventions offered by specialists, evaluating capacity to consent issues, and securing surrogate consents, when indicated, for needed medical interventions? If not, or if it is questionable, what steps can be taken to foster staff's understanding of these matters?

Agency Self Assessment

1. Could this happen in our program? Yes No
2. What lessons, if any, are applicable to our program?

3. Are there steps we should take to reduce the risk of similar problems in our program?

4. Person/Department responsible for follow-up.

5. Expected date of completion of actions identified in question number 3.

Additional Notes

In the Matter of Lester Banks*

A Recreational Accident

Case #31

The Incident

On a rainy morning, the last Saturday of summer, Frank Orvis was driving to the group home where he worked. As he turned onto the group home's street on the final leg of his journey, he pulled behind a 15-ton delivery truck. His dashboard clock indicated it was 8:30.

Mr. Orvis followed the truck, going the posted 30 MPH limit. As the vehicles neared the group home, Mr. Orvis noticed a person in a black hooded sweatshirt on a bicycle in the residence's driveway. The bicyclist was riding down the 100-yard driveway; he pedaled directly into the side of the oncoming truck, which was unable to stop in time or avert collision.

The bicyclist, Lester Banks, was one of the group home's residents. He suffered massive head trauma in the accident and died two days later in a local hospital.

The truck driver, who had a spotless driving record, was not cited for any violations of the Vehicle and Traffic Law in what proved to be a truly tragic accident.

Background

Lester Banks was a 24 year-old man who was diagnosed as being mildly mentally retarded. Since the age of eight, he had lived in a variety of out-of-home placements, including foster care, psychiatric hospitals and group homes, due to his explosive and impulsive behaviors. His mother, who was also mentally retarded, was unable to manage his behaviors which included fire-setting, running away, threats of suicide, and violent temper tantrums.

In addition to retardation, Mr. Banks was assigned various psychiatric diagnoses over the years; these included atypical psychosis, conduct disorder and adjustment disorder, to name a few. Medically, Mr. Banks enjoyed relatively good health; he did, however, have a profound hearing loss in one ear and required glasses to correct his vision.

When he was 19, Mr. Banks was placed in an out-of-state residential program. At the time of placement, Mr. Banks displayed daily episodes of aggression, property destruction, and other anti-social behaviors. Within the next four years, these behaviors dissipated and Mr. Banks, then 23, was referred to an agency which operated group homes on Long Island. Mr. Banks was placed in one of the agency's group homes which served seven individuals.

According to the home's records, Mr. Banks was a very high-functioning individual. He was independent in most areas of self care, had a great sense of humor and tended to socialize more with staff than his fellow residents. He enjoyed riding a mountain bike which he owned, writing letters to friends, and keeping a journal of his daily activities and desires. Journal entries detailed his fondness for staff, as well as his life goals: living in his own apartment, learning to drive a car and getting a "bigger and better job."

Most telling about Mr. Banks were comments offered by staff during interviews following his fatal accident. More than one staff person said they weren't sure whether Mr. Banks was a

* All names are pseudonyms.

staff person or a resident when they first met him. One staff member described him as a "peer;" another described his interactions with Mr. Banks as "more of a friendship relationship than a [staff-] client [relationship];" another, who was his primary counselor in the residence, said Mr. Banks was "bright and aware that he was different from his roommates...that's why it was difficult for him to receive help from professionals...he thought he was just like staff, and staff often treated him like a staff member."

While in the group home, Mr. Banks displayed none of the aggressive behaviors which had marked his earlier years. He was employed in a supported-work program at a local department store. In addition to fostering his vocational goals, his most recent service plan focused on skills that would advance his quest for more independent living: banking, cooking, and basic academic and travel skills.

Some Limitations and Problems

Although very high-functioning and having conquered his earlier behavior-control problems, Mr. Banks did have some limitations which posed problems. He tended to overestimate his abilities and, because of cognitive limitations, he sometimes showed poor judgement. He would periodically leave the group home without telling staff, or, while with a group of residents out on shopping trips, leave the group and wander off on his own. On one occasion, while waiting alone in the house van for a staff person, who had left the keys in the ignition, Mr. Banks started the vehicle, threw it in gear and attempted to drive himself. Driving erratically, Mr. Banks came to rest on the front lawn of the residence — no one was injured.

On another occasion, just months before his death, Mr. Banks left the house without permission and rode his bike — not wearing a helmet — several miles on heavily trafficked streets to a bank in town. He withdrew some money and returned home.

Investigation Findings

Like the police investigation into Mr. Banks' fatal accident which found no wrong-doing on the part of the truck driver, administrative investigations cleared group home staff on duty that morning of any culpability. The administrative investigations, however, found other problems in the group home's operations which set the stage for the Saturday morning tragedy. These included:

- Unclear expectations as to the conditions under which Mr. Banks could ride his bike;
- A lack of clear policies on the use of recreational vehicles, such as bikes and skateboards;
- The absence of an up-to-date comprehensive service plan for Mr. Banks which would inform all staff of, among other things, his needs for supervision; and
- The failure to formally communicate critical incidents involving Mr. Banks for review and possible modifications of service delivery plans.

In the absence of formal communication channels among staff (via service planning and incident reporting processes), residence staff relied heavily on "word-of-mouth" as a primary communications channel. As a self-assured, very high functioning individual who was perceived to be more like staff of the group home than a client, Mr. Banks was often the source of the "word-of-mouth" information about himself.

Interviews with staff after the accident revealed that Mr. Banks' bike riding abilities were questionable and that staff had differing understandings of what level of supervision he required while riding.

While some staff believed Mr. Banks was an able bicyclist, others stated he was "spastic" and "unstable" on the bike.

Following the incident wherein Mr. Banks rode to town unbeknownst to staff and not wearing his helmet, a staff member counseled him on the dangerousness of his actions. The staff person also wrote in Mr. Banks' "program book" that Mr. Banks "is not to ride his bike unless a staff member is present...He must wear a helmet at all times...The problem being, in the past he has taken his bike and left home without permission...This is a potentially dangerous situation."

This incident was not formally reported and reviewed by the agency, and Mr. Banks' service plan was not updated to reflect his special supervision need with regard to bike riding.

Immediately following the bicycling-to-town incident, Mr. Banks' bicycle was put in a utility room and a lock was placed on it, thus limiting his unfettered access to the bike. Subsequently, however, the lock was needed for another purpose in the home and was removed, thus allowing Mr. Banks free access to his bike.

In the subsequent weeks, Mr. Banks routinely used his bike to ride up and down the home's long driveway as a form of exercise. All staff were aware of this, as Mr. Banks would post this early morning routine on his daily calendar of activities.

However, staff were not consistent in ensuring that Mr. Banks was supervised during this activity. Some believed that Mr. Banks did not require supervision while riding in the driveway. Others were convinced that it was OK by Mr. Banks himself who would report "I'm just going to get the newspaper" (at the driveway's end).

During this early morning routine, Mr. Banks was periodically seen not wearing his helmet. When this was observed and Mr. Banks was reminded to put on his helmet, he would sometimes comply, or put his bike away, as he disliked wearing the helmet.

On the morning of his fatal accident, Mr. Banks told staff that he was going to step outside for a "breath of fresh air." Staff were not aware that once outside, he began riding his bike; nor were they aware he was not wearing his helmet, which was found in his room after the accident. It was estimated that Mr. Banks was outside for no more than 15 minutes when the accident occurred.

Lessons Learned

Questions linger about the more immediate factors contributing to Mr. Banks' accident. How able a rider was he? Did he not see the truck coming? Was his already slightly impaired vision further compromised by rain on his glasses or the hood of the sweatshirt he was wearing? Given his hearing loss, did the hood of the sweatshirt further impair his hearing? Did he not hear the truck, its horn? Was his judgment poor? Did he overestimate his or the truck's ability to stop on rain-slicked pavement? Or did he not notice anything, perhaps engrossed in thoughts of what the rest of Saturday held in store?

Some questions had haunting answers. If Mr. Banks had received the level of supervision one staff had prophetically indicated was needed in order to protect him, perhaps the accident could have been avoided. Had Mr. Banks worn his helmet, as staff believed he should — but he didn't like to do — perhaps his injuries would have been less severe; perhaps he could have survived to achieve his desired life goals.

Honoring and fostering consumers' everyday interests is a vitally important role played by service providers. It also has attendant risks, which providers must be mindful of and safeguard against. Sometimes the risks associated with some of these interests are readily apparent, for example, risks associated with learning cooking skills, independent travel skills, or vocational skills in industrial settings.

Risks associated with leisure time or recreational interests, however, are often less appreciated.* After all, swimming, bike riding, hiking, etc. are things we all do to relax, to take pressure off. They are things we do when we want to have fun and not work.

Lester Banks' death taught his agency that it did not pay sufficient attention to the leisure-recreational interests of clients in a way that would promote abilities and at the same time safeguard against harm. Had Mr. Banks engaged in serious maladaptive behavior, such as fire setting, assault, etc., as he had done in the past, it would have been amply documented, reviewed and communicated to all staff. But when he engaged in a healthy recreational activity which potentially posed as serious a risk of harm, it was not well documented, appreciated and communicated to all staff.

In response, the agency instituted certain policy reforms which are worthy of consideration by all agencies. Among the questions addressed by the agency which other providers should probe are:

- Does the agency assess and document individuals' skills, as well as their understanding of safety rules and precautions, in leisure/recreational activities such as bike riding, swimming, skate boarding and sports which may carry a risk of harm?
- Are levels of supervision for certain recreational activities agreed upon based on assessments of individuals' skills?
- Is there a universal understanding of what safety or protective equipment is required for different types of activities (e.g., helmets for bicycling, protective pads for skateboarding and ice skating, etc.)?
- Are recreational equipment and protective devices properly maintained and in good working order?
- Is equipment stored in such a way that access can be controlled, if necessary, and proper use also promoted?

Agency Self Assessment

1. Could this happen in our program? Yes No
2. What lessons, if any, are applicable to our program?

3. Are there steps we should take to reduce the risk of similar problems in our program?

*See *In the Matter of Matthew Sweet*, Case #3.

4. Person/Department responsible for follow-up.

5. Expected date of completion of actions identified in question number 3.

Additional Notes

In the Matter of Francine Charlot*

Preventing Pulmonary Emboli Case #32

Background

In life, Francine Charlot was a clerk with the Department of Motor Vehicles. Her death, at age 49, was a driving force in changing policies at a local hospital to better protect the health and safety of countless future patients.

Ms. Charlot emigrated to the States with her parents and three younger brothers from her Caribbean-island homeland when she was 25 years old. Little is known about her early years. She had completed 10 years of school, and was close to her parents and siblings. She was also soft-spoken, well dressed and friendly.

Soon after her arrival in the States, Ms. Charlot was hospitalized for major depression with psychotic features. Reportedly, she became depressed over a failed relationship with a man and had isolated herself in her bedroom, staying in bed "all covered up" days on end.

Following this hospitalization, Ms. Charlot continued to live at home with her family in New York City. Over the years, her younger brothers married and moved out. She spent her days at home, cooking and cleaning for her aging parents and enjoying her role as aunt of her brothers' children. She was personable, but had few close friends and spent most of her time at home. She did, however, attend an outpatient clinic where she was seen by a psychiatrist, for medication purposes, and a social worker for counseling.

Twenty years after her first hospitalization, Ms. Charlot was again hospitalized for recurrent major depression with psychotic features. A secondary diagnosis of mixed personality disorder with dependent features was added, as were medical diagnoses of hypertension and glaucoma.

During her three-week hospitalization, Ms. Charlot was treated with antidepressants; she was discharged to live with her parents.

Following discharge, Ms. Charlot was enrolled in an outpatient program which offered vocational training services. Through its assistance, she honed secretarial and clerical skills, first attained in business school in her homeland, and was placed in her first out-of-home job as a part-time clerk with the Department of Motor Vehicles. Ms. Charlot continued outpatient treatment while working; her diagnosis was major depression with psychotic features in remission.

In the summer of her 49th year, however, Ms. Charlot stopped taking her daily medications, Triavil 50 mg and Ambien 10 mg.

Final Hospital Admission

Ms. Charlot decompensated over a three week period. She complained of hearing voices, feeling depressed and being scared and preoccupied with death.

On July 31, Ms. Charlot's mother brought her to the emergency room of a local hospital. Ms. Charlot's speech was incoherent and rambling, she appeared disheveled and was agitated. Although denying suicidal ideation, Ms. Charlot did not cooperate with a mental status exam. She was admitted with the initial diagnosis of paranoid schizophrenia and started on Stelazine and Ativan PRN for agitation.

*All names are pseudonyms.

During her first hospital day, Ms. Charlot refused meals and was agitated, requiring PRN medications. By her second day, Ms. Charlot was selectively mute and refused medications, food and fluids. As the day progressed, Ms. Charlot became unresponsive to verbal stimuli. She was sweating and had a fixed stare. With the exception of Procardia, which was started for tachycardia when she was admitted, Ms. Charlot refused all medications.

A psychiatrist was summoned who noted that Ms. Charlot was selectively mute, and experiencing some stiffness, localized sweating and fluctuations in blood pressure. His tentative diagnosis was rule out Neuroleptic Malignant Syndrome vs. Catatonia. His plan was to discontinue Stelazine, start Ativan 2 mg po every four hours for catatonia, and request a medical consult.

A medical specialist who examined Ms. Charlot was of the opinion that she was not experiencing NMS and that her muteness and rigidity, which appeared to be voluntary, were the result of her psychiatric condition.

By evening, Ms. Charlot became very agitated, pacing the hallways with her eyes closed. When redirected back to bed, she would not stay there. Even with bed rails in the upright position, Ms. Charlot would not stay in bed; in a disorganized state she would attempt to climb over the rails, placing her at risk of harm. As such, restraints were ordered.

Over the course of hospital day three, Ms. Charlot remained in restraint. Her temperature rose to 103 degrees and her blood pressure fluctuated between 120/80 to 170/100. She was also delusional and was seen by psychiatric and medical specialists. Her condition raised the possibility of Neuroleptic Malignant Syndrome or infection, and she was transferred to a medical service for treatment of NMS and further diagnostic tests and treatments for infection.

Over the next five days while on the medical unit, Ms. Charlot was followed by both medical and psychiatric services. When she wasn't mute and resting in bed, she was agitated, requiring mechanical restraint in bed. She essentially spent the last days of her life immobile. As she wouldn't regularly take nourishment, she was placed on IV hydration.

During this period, she was treated prophylactically for NMS and she also underwent tests for possible infections which, as the results came in sometime after her death, proved to be negative.

On her sixth day on the medical service, a nurse released Ms. Charlot from her restraints to reposition her in bed. As Ms. Charlot was being turned, she gave a large sigh, and expired.

Upon autopsy, death was attributed to a pulmonary thromboembolism due to deep vein thrombosis due to catatonia.

Lessons Learned

Investigations into Ms. Charlot's death raised several areas of concern.

First, it was noted that although Ms. Charlot was refusing food and fluids and required IV hydration, documentation of the level of her oral and IV intake was inconsistent. This was largely a documentation problem, as blood chemistries indicated that she was not dehydrated; nursing staff were reeducated on the importance of monitoring and documenting intake and output.

Similarly, for a two-day period of Ms. Charlot's stay on the medical service, there were gaps in documentation pertaining to restraint. The need for restraint was apparent in the record, but evidence that Ms. Charlot was released from restraint for range of motion exercises, as called for by facility policies, was missing. Nursing staff were counseled on this matter.

But more importantly, the investigations into Ms. Charlot's death led to the development of a treatment protocol to prevent future catastrophic ends.

For the last week of her life, Ms. Charlot was immobile: either bedridden in a catatonic state, or restrained in bed during periods of agitation. Prolonged periods of immobility place patients at risk of developing phlebitis, deep vein thrombosis and pulmonary emboli, which was Ms. Charlot's fate.

In response, the hospital developed a treatment protocol for the prevention of pulmonary emboli, identifying at-risk populations and preventive interventions.

The hospital's protocol identified the following individuals to be at risk of pulmonary emboli:

- Patients with catatonia;
- Severely depressed patients who are bedridden;
- Elderly patients who do not ambulate;
- Patients immobilized by fractures or weakness;
- Patients in restraint for prolonged periods; and
- Patients whose mobility is markedly decreased due to medications.

Among the preventive interventions called for by the hospital's protocol for these at-risk populations were:

- Assisting the patient to ambulate every two hours;
- Assisting the patient to a sitting position without legs dangling;
- Elevating legs every three hours to minimize stasis and increase venous return;
- Encouraging complete range of motion, including toes, feet and legs;
- Applying elastic stockings; and
- Placing high-risk patients on anti-coagulant drug therapy.

According to the hospital policy, all psychiatric patients' risk status for pulmonary emboli will be assessed by their psychiatrists, who will order the appropriate level of intervention needed and consult with medical specialists for high risk patients who may require the use of anti-coagulant therapy.

Considerations for Other Agencies

The lessons learned by Ms. Charlot's acute care provider are worthy of consideration by other care providers, be they acute-care or long-term service providers. Acute-care service providers should consider:

- Are all staff aware of agency policies concerning the use of restraint and safeguards put in place to monitor and protect individuals in restraint (i.e., standards for release from restraint, range of motion, documentation concerning monitoring, etc.)?
- Are nursing staff aware of documentation expectations concerning basic care, such as monitoring intake, output, vital signs, etc? And are these expectations reinforced through supervision?
- Should the agency develop a standard protocol for the prevention of pulmonary emboli, as Ms. Charlot's facility did?

Providers of long-term care often serve individuals who periodically require acute, inpatient hospital care. Sometimes these individuals require the intervention of restraint, or other aspects

of their condition place them at risk for pulmonary emboli. Long-term care providers can serve as these individuals' advocates by:

- Becoming familiar with factors which place an individual at-risk for pulmonary emboli;
- Establishing a rapport with the acute care providers to allow an exchange of information with the provider on the patient's condition; and
- Suggesting, encouraging or advocating for interventions to prevent pulmonary emboli, if the patient's condition presents the risk of such.

Agency Self Assessment

1. Could this happen in our program? Yes No
2. What lessons, if any, are applicable to our program?

3. Are there steps we should take to reduce the risk of similar problems in our program?

4. Person/Department responsible for follow-up.

5. Expected date of completion of actions identified in question number 3.

Additional Notes

In the Matter of Joseph Fitzgerald*

Failure to Seek Prompt Medical Care Has Tragic Consequence Case #33

Background

Joseph Fitzgerald was the youngest of five children. From the moment of his birth it was evident that Joseph would face multiple challenges for the rest of his life. Born with Down's syndrome, he would later test as functioning within the severe range of mental retardation. Yet, despite a rather harsh prognosis, and with much encouragement from his family, Joseph learned to walk, talk (although he was difficult to understand), dress himself, and perform many of his ADL skills independently.

Mr. Fitzgerald was also born with a deformity called *esophageal atresia*. This congenital condition meant that Mr. Fitzgerald's esophagus was not connected to his stomach, making feeding or eating impossible. After a number of surgeries to repair his esophagus, Mr. Fitzgerald was able to begin eating normally. As a result of his numerous operations, a small pouch remained in his esophagus. In order to prevent food from collecting in this area, Mr. Fitzgerald learned to cough and to manually stroke his neck as a means to empty the pouch.

Mr. Fitzgerald remained at home with his family until he was in his twenties. At this point his family felt that he would benefit socially from placement in a residence in the community. An additional consideration for his parents was the inescapable fact that they were aging, and they were concerned about providing for Mr. Fitzgerald's future. Eventually he was placed in a community residence and attended a workshop program on a daily basis. Although Mr. Fitzgerald was at risk for aspiration due to his esophageal pouch, and his tendency to eat large bites rapidly, there were no recorded incidents of choking or aspiration while he was at the residence. His service plan adequately addressed the risk associated with eating. For nearly a decade Mr. Fitzgerald lived a relatively healthy and active life at the residence.

The Incident

As a Friday night treat, Mr. Fitzgerald's house decided to order Chinese food for dinner. Mr. Fitzgerald ate a large portion and, while still at the table with the other residents and staff, he began to display inappropriate behavior. In accord with his behavior plan, staff tried to re-direct him and, when these efforts failed, staff sent Mr. Fitzgerald to his room. After a short time period in his room (approximately 10 minutes), Mr. Fitzgerald returned to the dinner table. He followed his usual routine for the rest of the evening.

Just prior to sunrise on Saturday morning, a staff member heard Mr. Fitzgerald groaning in his room. He pointed to his stomach and the staff person noted that his abdomen was hard and distended. After the staff person rubbed his back for a short period of time, Mr. Fitzgerald said he felt better. Following this, staff began hourly checks on Mr. Fitzgerald.

During morning rounds, staff reported that Mr. Fitzgerald still wasn't feeling well. The staff on duty took his temperature and indicated that it was "a little high." However, the temperature was documented as 96.7° axillary. The axillary method of taking a temperature is the least accurate and generally reads 1° to 2° lower than oral temperatures. Tylenol was given, but not

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recorded on the medication documentation form. A short time later Mr. Fitzgerald was incontinent of stool, which was unusual. Staff made the decision to keep him out of the Day Program and continued to check on him hourly.

At noon, staff noted that Mr. Fitzgerald was lying naked on top of his bed shivering, sweating, and his skin was clammy to the touch. No temperature was taken. Staff also reported that his cough was different than his usual throat-clearing cough, and he was wheezing. At 4:00 PM his axillary temperature was 101.8°.

The House Manager, Ms. Marilyn Spratt, was beeped by one of the house staff and notified of Mr. Fitzgerald's illness. Ms. Spratt instructed the staff to give Mr. Fitzgerald Tylenol if his temperature was above 101°. It was noted by staff that the form for Mr. Fitzgerald's over-the-counter medications had expired several weeks ago, and the new form was not in the house. Ms. Spratt instructed the house staff to administer the Tylenol nevertheless.

Over the next several hours, Mr. Fitzgerald's axillary temperature was recorded as ranging from 102.4° to 102.9°. He had a low blood pressure which was not recorded, and a "fast pulse." Later that evening, Ms. Spratt arrived at the house. She proceeded to take his temperature, which was recorded as 103.6° orally. Ms. Spratt noted no difficulty with Mr. Fitzgerald's breathing and administered more Tylenol. One staff person questioned whether Mr. Fitzgerald should be sent to the hospital. Ms. Spratt indicated that she did not consider Mr. Fitzgerald to have an emergent condition. Ms. Spratt remained at the house overnight in her bedroom.

No vital signs were taken for the next seven hours. Early Sunday morning, Mr. Fitzgerald's axillary temperature was recorded as 98.9°. Throughout the day his vitals were reported as "normal" but never recorded. He had been refusing to eat for 24 hours and he had ingested only a small amount of fluids within the same time period. Staff described finding him several times on top of his bed in varying stages of undress.

Ms. Spratt went in to check Mr. Fitzgerald at 5:30 PM and noted immediately that he "didn't look right." She reported that he sat up, shook his arms, and slid off the bed. Interpreting this act as being a playful gesture, Ms. Spratt left Mr. Fitzgerald's room and returned a few minutes later. Upon returning, Ms. Spratt noted that Mr. Fitzgerald had not moved. She became concerned, sat him up against the bed, and within moments, he stopped breathing. A 911 call was placed immediately and Ms. Spratt and another staff person began CPR; however Mr. Fitzgerald could not be revived. The autopsy revealed that he died of pneumonia, just two days before his 35th birthday.

What Went Wrong?

A thorough investigation by the agency which ran the house indicated that direct care staff and the house's management team exhibited poor judgement, specifically:

- Despite policy, the House Manager, Ms. Spratt, had promoted an informal beeper system with her staff. House staff were encouraged to funnel all client and house concerns through the manager via her personal pager when she was out of the house or off-duty. Ms. Spratt then made the decisions on who was to be notified for specific problems and then she would provide the notifications. The Program Coordinator, who provided the oversight for Ms. Spratt, was aware of this system and did not discourage it.
- Ms. Spratt, the House Manager, made medical decisions that she was not qualified to make.
- Staff were aware that several clients in Mr. Fitzgerald's Day Program class during the past week had respiratory infections requiring treatment with antibiotics. One client was hos-

