
Could This Happen in Your Program?
A Collection of Case Studies Provoking Reflection,
Discussion, and Action

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FOR THE MENTALLY DISABLED



About: Could This Happen In Your Program?

Could This Happen In Your Program? is a series of case studies designed to provoke reflection, discussion and, where indicated, action by staff of mental hygiene agencies to ensure that they and their agencies provide maximum protection and quality care for the people they serve.

Drawn from the investigative files of the Commission on Quality of Care for the Mentally Disabled, each study presents the facts and lessons learned from tragedies encountered by the Commission.¹

As an overseer of New York State's mental hygiene service system and an advocate for its consumers, each year the Commission, among other things, reviews and investigates thousands of consumer complaints, allegations of abuse or neglect, and unusual deaths or deaths due to other-than-natural causes. Each investigation results in a report addressed to the service provider, usually in the form of a letter, presenting the Commission's findings, and, where necessary, recommendations to improve consumer services. On a fairly routine basis, the Commission has profiled the findings of its individual case investigations in its bi-monthly newsletter, *Quality of Care*.

Experience, however, suggested that these means of communication alone were not sufficient in achieving the Commission's ultimate goal of assuring that the care of persons with mental disabilities is of a uniformly high standard. Too often, deficient conditions identified and corrected at one facility as a result of a Commission investigation, resurfaced later with tragic results at another facility across town, or across the State; the lessons learned by one facility through tragedy were not heard or replicated by the other facility, despite the fact that the Commission had issued a report, available to the public under the Freedom of Information Law (FOIL), and may have profiled the case in its newsletter, which is sent to the Directors of all mental hygiene facilities.

Realizing that reports available under FOIL are infrequently requested by the public generally and staff of mental hygiene facilities in particular, and that newsletters rarely make their way from executive suites into the hands of people on the front lines of service delivery, the Commission determined that another mode of communication was in order to reduce the potential for preventable tragedies: one which lent itself to wide dissemination within the mental hygiene service community; one which compellingly engaged the reader in real-life situations; and one which prompted readers to discuss their own agency operations, to question "could something like this happen here?" and to act to ensure it didn't by revising or re-articulating agency policies, by providing additional staff training or by otherwise modifying program operations. With that realization, the series of case studies, *Could This Happen In Your Program?* was born.

Abstracted from the Commission's files, each case study presents the facts of a situation reviewed or investigated by the Commission and, more importantly, discussion points, or lessons learned, to draw readers into a reflection on the adequacy of their own agency's operations relative to the case profiled. The brevity of the case studies is intentional. Today's world of service delivery offers little time for staff training, and resources dedicated for education are shrinking. In their brevity, the case studies are designed to facilitate easy duplication and dissemination, to provide a quick and easy read for all staff, and, above all, to leave a lingering question which only staff's discussion and practical action can resolve, "Can this happen here?"

The Commission piloted *Could This Happen In Your Program?* in 1993 by sending three draft case studies to several facilities in New York State. Their overwhelmingly positive response as to the utility of the studies as staff training vehicles affirmed the value of this quality assurance tool.

¹ Names appearing in the case studies are pseudonyms and care is taken not to divulge the identity of service providers.

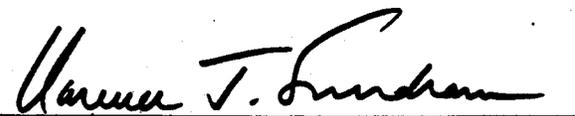
Since 1994, the Commission has disseminated nearly 100,000 copies of case studies free of charge to service providers in New York State, 40 other states as well as several foreign countries. With each mailing, the Commission has invited the recipient to duplicate and disseminate the case studies as widely as he or she feels fit as staff training tools. The case studies won a 1995 award from the National Association of Mental Health Information Officers; have been profiled in several professional journals, including *Mental Retardation*, *Psychiatric Services*, *New Directions*, and the *National Association for Regulatory Administration Newsletter*, and have received unsolicited accolades from recipients, some of which are reprinted herein.

This compendium offers a complete set of the case studies written to date and sent to service providers at various points in time over the past nearly three years.

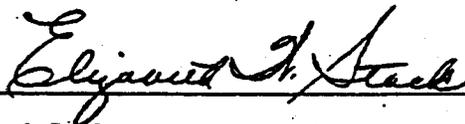
The anthology has been produced in such a way that its recipients can easily duplicate complete sets of the case studies and package them in three ring binders or include them in other training manuals. Additionally, space has been provided following each study to allow the reader to make notes or record his or her own questions, concerns, or intended actions.

The Commission offers this first volume in a continuing series of case studies with the hope that it will better enable you and staff of your agency to be all that you can be in the protection and care of the people you are entrusted to serve. The Commission invites you to duplicate the studies and disseminate them for use as widely as you see fit. Also, as always, we welcome your feedback.

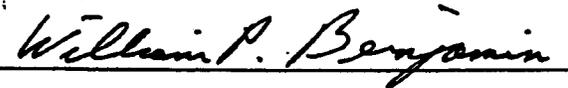
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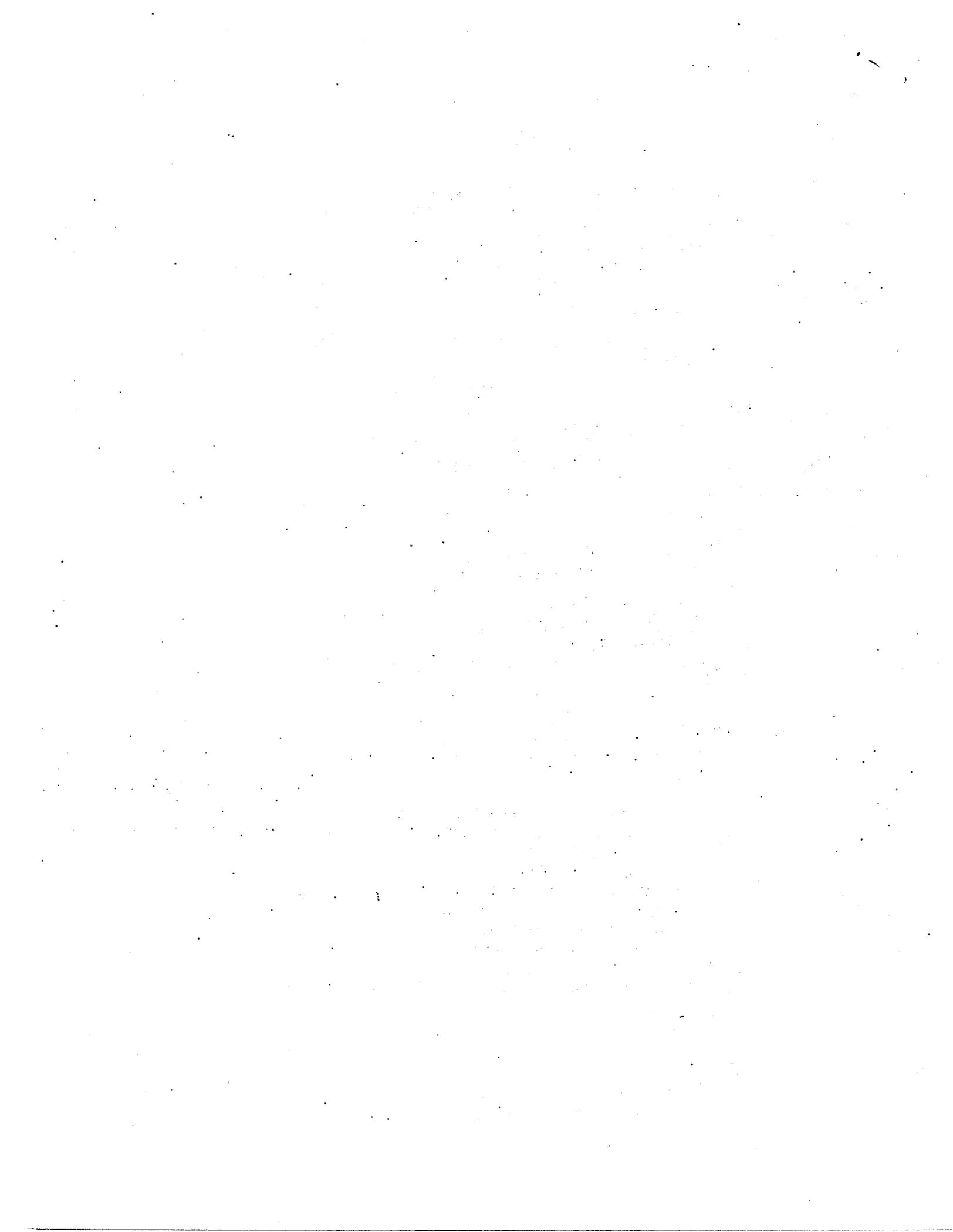
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Acknowledgements

This volume is dedicated to the men, women and children whose stories are told here. There can be no measure of the cost of the lessons, as they were paid for, so often, in pain, suffering, and even death. The only fitting payment is the resolve that no one else will pay again.

The Commission also acknowledges the efforts of current and former staff in preparing this case-study training tool which we hope will assist programs in assuring the protection and quality of care of the people they serve.

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In the Matter of Michael Henry:

A Case of Flawed Risk Assessment and Discharge Planning

Case #1

Background

Michael Henry¹ was a 27-year-old man who, within hours of release from a psychiatric facility, committed suicide.

Employed and married, Mr. Henry had no history of mental health treatment until the spring of 1992, when his wife left him.

Within a week of the separation, his place of employment—through its Employee Assistance Program—referred Mr. Henry to a private therapist, as it appeared he was depressed. During the first visit, Mr. Henry reported that his wife had left him and that he was estranged from his own family. Since the separation, he indicated, he had been unable to sleep and eat, and had lost more than ten pounds. He also reported that with the separation, he was now estranged from his wife's family, with whom he had been close, and he had only one friend.

Preliminary Diagnosis/Treatment

The therapist recorded that Mr. Henry appeared depressed, with flattened affect and slowed speech and movement, and was suffering from an acute grief reaction. Her diagnosis at the time was Adjustment Disorder with Mixed Emotional Features. She arranged for Mr. Henry to be seen that day by a general practitioner. The therapist also scheduled him for a follow-up appointment in two days, on May 15. The private physician who examined Mr. Henry found no medical maladies, but noted the significant loss in his life, his inability to eat or sleep, and the therapist's impression of grief reaction. The physician prescribed Zoloft 100 mg q a.m., and Sinequan 25 mg hs; he also encouraged Mr. Henry to continue with counselling.

On Friday, May 15, Mr. Henry kept his follow-up appointment with the therapist. He reported that the doctor had prescribed two medications, but he couldn't remember their names. His affect appeared very flat, and he expressed hopelessness over his marital situation, stating that he did not think he could go on without his wife. During the session, Mr. Henry denied suicidal ideation. The therapist attempted to give him her home phone number in case of an emergency, but he refused to take it. He did, however, reluctantly agree to another appointment on Tuesday, May 19. After the visit, the therapist called the private physician to express her concern that Mr. Henry may overdose on the medications.

On Monday, May 18, Mr. Henry failed to show up for work. His supervisor called him at home, and alerted his therapist. In the ensuing conversations, Mr. Henry stated that he thought it was his day off. He also reported that he had stopped taking his medications as they upset his stomach. He promised that he would report for work the next day and keep his therapy appointment as well.

Suicide Attempts

That afternoon, however, Mr. Henry was found in the bathtub by his wife, who had stopped by to visit. He had cut one of his wrists. Mr. Henry was taken to the emergency room of a local hospital where his wound was sutured. He reported that he was depressed and had cut himself because "it seemed like the right thing to do"—he had found out that his wife had left him for his only friend. He also reported that he ingested all of his medications the previous Saturday "in an attempt to sleep." A suicide note and empty pill bottles were found in his apartment.

Emergency Room Activity

The emergency room physician contacted Mr. Henry's therapist to express concern that he was at high risk and should be admitted to a psychiatric facility. She agreed. That night, Mr.

¹ A pseudonym.

Henry was transferred to another community hospital, which had an inpatient psychiatric service, and was examined.

The examining psychiatrist deemed that Mr. Henry was depressed, actively suicidal and at high risk, although he denied suicidal ideation. During the mental status examination, it was also noted that Mr. Henry was not honest with himself or others. The psychiatrist ordered that Mr. Henry be admitted on an involuntary basis. As the psychiatric service was at capacity, he was to be held in the emergency room on suicide and escape precautions until a bed became available. The admitting diagnosis was R/O Major Depression Single Episode.

The next morning, May 19, while still in the emergency room, Mr. Henry was seen by an aide, who noted that Mr. Henry claimed that he truly did not attempt suicide. "Why would I cut my wrist when I have a gun in the closet?" Mr. Henry was recorded as stating. The aide also noted receiving a telephone call from Mr. Henry's therapist. According to the aide's note, the therapist indicated that she had seen Mr. Henry several times and, although he appeared mildly depressed, he did not appear suicidal. According to him, she reported that Mr. Henry had very few, if any, supports, and she requested to be appraised of discharge plans. The therapist's contemporaneous notes of this conversation indicated she called the hospital "to warn" staff that Mr. Henry does not present himself accurately and had no support system; she was assured that the patient would be admitted for a short stay and would not be discharged until he was safe, and she would be informed of the discharge.

At noon on May 20, Mr. Henry, still in the emergency room, was seen by a different psychiatrist than the one who admitted him the previous evening. This psychiatrist recorded that the patient was eager to leave the facility and "get back to work." The psychiatrist recorded that he did not believe Mr. Henry was at risk for suicide, and recommended discharge with "some home support...for counselling follow-up." The physician's diagnosis was Adjustment Disorder with Depressed Mood.

A while later, Mr. Henry's mother and sister came to the hospital to visit Mr. Henry, under the impression that he had been admitted. Instead, they found him in the emergency room.

Discharge

The mother and sister did not have an opportunity to speak with the psychiatrist. Rather, they were told by nursing staff that Mr. Henry could go home. In a discharge note, an aide recorded, "Mom will supervise patient to see he's safe and follows through with therapy," even though Mr. Henry lived independent of his mother in a different town. Mr. Henry's outpatient therapist was not informed of the discharge.

Suicide

On the afternoon of May 20, family members drove Mr. Henry back to his apartment where he lived alone. That night he shot himself in the head with the gun he "kept in a closet." His therapist learned of the discharge after Mr. Henry inflicted the fatal injuries; she was requested to be available for crisis intervention services for the children in the school where Mr. Henry had worked.

Lessons Learned

The case of Mr. Henry illustrates the tragic outcome of flawed risk assessment and discharge planning. Staff of the hospital to which Mr. Henry was admitted were fully informed that he had made two recent suicidal gestures (overdosing and wrist slashing), written a suicide note, and was an unreliable reporter and had no support system, yet he was allowed to leave the facility to live alone less than 24 hours after his involuntary admission.

It appears that a psychiatrist made a unilateral decision that Mr. Henry was not at risk of self-harm and thus released him. The physician arrived at this conclusion based on Mr. Henry's own statements, without the benefit of a lethality assessment and without speaking with the admitting physician, who found Mr. Henry actively suicidal and at high risk. He also did not speak with Mr. Henry's outpatient therapist who called the hospital "to warn" that Mr. Henry was not a reliable reporter of events, and to request involvement in discharge planning, or with family members.

Critical Unanswered Questions

Absent a full history and aftercare plans developed on the basis of consultations with other clinicians and family members, a decision to release Mr. Henry was made while a number of critical questions remained unanswered, including:

- Did Mr. Henry live alone or in a supervised setting?
- Was there a gun in the residence, as Mr. Henry reported?
- What, realistically, could family members provide in terms of "supervision," when they lived in a different town?
- Where was Mr. Henry to go for counselling and other clinical services—including medication management, if warranted—following discharge, and when was his next appointment?
- Finally, and most importantly, did Mr. Henry have plans, goals and commitments for tomorrow, for the next day, for life?

Assessing the potential for, and preventing, dangerous behavior is one of the most serious tasks confronted by clinicians—and one faced daily by staff of hospital emergency rooms. As demonstrated by the case of Mr. Henry, it is a weighty labor, and one that need not, and should not, be shouldered alone.

Hospitals and other psychiatric facilities should review their policies and practices to determine to what extent they affirmatively promote the input of other clinicians, inpatient and outpatient providers, and family members, in addition to the patient, in decisions pertaining to the retention of patients or their release and aftercare plans.

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 Mary Rose:
A Case of Unclear Standards and Expectations
in a Small Group Home
Case #2

Background

Mary Rose¹ was born in 1929. At the age of five, while undergoing an appendectomy, Mary sustained cerebral anoxia which resulted in brain damage. Mildly mentally retarded, Mary was verbal, ambulatory, able to read and write, and independent in her self-care needs. She lived with her father for 45 years and then, when his health failed, lived with her sister. During this time she attended a local day program for developmentally disabled persons and thrived.

In 1986, Ms. Rose, then 57 years old, moved into a community residence operated by the State Office of Mental Retardation and Developmental Disabilities (OMRDD). The move was precipitated by Ms. Rose's desire to live in a "place of her own" and the stress placed on family members who had cared for her over the years. After the move, Ms. Rose's sister maintained contact with her through telephone calls and visits.

In the following years, Ms. Rose generally enjoyed good health, although she suffered from osteoarthritis and required the use of a walker. She was also noted to be a picky eater, and her food intake had to be monitored, as she was about 15 pounds below her ideal body weight. (At one point she had dropped to more than 20 pounds below her ideal weight; no medical cause for the weight loss could be found, and in time she regained the lost weight.)

Abdominal Pain

In the summer of 1992, Ms. Rose was transferred to another OMRDD-operated residence in order to be closer to her family. In the weeks prior to the move, Ms. Rose visited the new residence several times for trial overnight stays. During the visits she complained of abdominal pain and vomited. She also refused to eat certain meals, claiming she was afraid it would upset her stomach. Staff believed that Ms. Rose was "just homesick." However, she also vomited several times when she returned from the trial visits. Staff of that residence believed that Ms. Rose was anxious over the impending move; staff of neither residence notified nursing or medical personnel.

On July 14, Ms. Rose moved to her new home. That night she vomited. She did so again several times the next day, and staff recorded that she had a "nervous stomach," was uneasy over the move, and had eaten little over the past two days.

Staff (In)actions

On the third day in her new residence, July 16, Ms. Rose ate very little breakfast, and refused lunch and dinner. She also fell once, sustaining a bruise on her head. An evening-shift staff member called the Administrator On Duty (AOD) to express concern about Ms. Rose's poor food intake and fall. The AOD concluded that Ms. Rose's refusals to eat were behavioral in origin and advised the evening aide to observe Ms. Rose for any further injury resulting from the fall.

The next day, while off duty, the evening staff member called another administrator to express concern over Ms. Rose's limited food intake and fall the previous night. A nurse was sent to the residence to check on Ms. Rose. The nurse's recorded examination, however, was limited to determining whether Ms. Rose could bear weight and whether there was any hip or coccyx pain as a result of the fall. She did not record a full nursing assessment (i.e., vital signs, abdominal examination, etc.). And, although the nurse advised staff to record Ms. Rose's food intake, they did not consistently do so in the following days. Nor did they monitor or record her vital signs.

That evening, July 17, Ms. Rose refused all food. She also refused to participate in a fire drill. She would respond to staff's requests and prompts by curling up in a fetal position and screaming. Ms. Rose also fell several times and staff had to carry her as she refused to walk.

¹ A pseudonym.

or couldn't. She spent most of the night crying, but wouldn't answer when staff asked what was wrong.

The next morning, July 18, it was discovered that Ms. Rose had wet her bed. She appeared weak and tired and was unable to stand. Ms. Rose refused breakfast and lunch, but at one point ate a bowl of oatmeal and several cookies. She spent most of the day on the couch and was incontinent.

By dinnertime, Ms. Rose was so weak she couldn't hold her fork or cup. Staff attempted to feed her, but the food fell out of her mouth. Aside from periodic whines, Ms. Rose remained nonverbal and she would not respond to staff questions. Her eyes looked glazed.

The evening-shift staff member called the AOD to voice concern that Ms. Rose was refusing to eat and appeared weak. She was advised to coax Ms. Rose to eat and drink, to observe her closely, and to report back to the AOD at 10:00 p.m. At the appointed hour, the staff member reported to the AOD that Ms. Rose was still weak, but did drink a half glass of water every hour. The AOD instructed her to continue to observe Ms. Rose and to send her to the hospital if her condition worsened or if she refused breakfast the next day. Before going off duty, the evening-shift worker noticed that Ms. Rose had vomited black fluid and that her skin was cool and clammy. The worker changed the bed linens, washed Ms. Rose, and then left for the day.

Hospital Transfer

Two oncoming night-shift staff, noting that Ms. Rose had again vomited black fluid, were of mixed opinions as to whether she should be sent to the hospital immediately or whether it could wait until morning. No administrator was consulted. By 1:00 a.m. on July 19, when Ms. Rose would not respond to external stimuli, an ambulance was called. However, the staff person who placed the call gave the wrong address for the facility. More than an hour passed before this error was corrected and an ambulance was dispatched to the proper address.

Upon arrival at the hospital, Ms. Rose was unresponsive. She was diagnosed as having gastrointestinal bleeding, septic shock, renal failure, hypotension, hypothermia, and metabolic acidosis. A consultant called in on the case noted that Ms. Rose had multiorgan system failure and was clearly suffering from gastrointestinal bleeding. He speculated, based on laboratory tests, that an intra-abdominal catastrophe, such as a tear caused by vomiting, may have triggered the multiorgan system failure. Her prognosis was listed as extremely poor and, despite aggressive treatment in the ICU, she died that day. No autopsy was conducted at the family's request, and the death was attributed to adult respiratory distress syndrome due to septic shock due to abdominal source. In the opinion of the Commission's Medical Review Board, Ms. Rose died as a result of a condition neither appreciated nor diagnosed by OMRDD staff, and thus not treated in a timely fashion.

Group Homes

In New York State, over 20,000 persons with developmental disabilities live in small group homes such as the one in which Mary Rose lived. Intended to offer homelike living experiences for their residents, these homes tend not to be medically intensive facilities; their staff, by and large, are not medical professionals, and are trained to provide clients assistance and supervision in activities of daily living. Theoretically, these "frontline" staff are provided professional medical backup through the sponsoring agency—which may have nurses, physicians and administrators on call 24 hours a day—or community-based resources, such as hospitals, medical groups or physicians with which they may have affiliations.

Lessons Learned

The case of Mary Rose illustrates just how shaky this theoretical backup system can be unless it is fortified by very clear expectations for direct care staff as well as on-call nurses and administrators. The case raises questions which all agencies should consider in reflecting on their operations:

- Before attributing changes in residents' behavior to "emotional" or "behavioral" difficulties, are appropriate steps taken to rule out possible underlying medical causes for the changes? For days Ms. Rose had signs and symptoms of abdominal distress—vomiting, refusing to eat, episodes of crying, etc.—yet staff, including the AOD, attributed her behaviors to "homesickness" or anxiety over her new placement.

- Do direct care staff clearly understand *when* to call administrative or medical backup and *what* to report? Significant changes occurred with Ms. Rose which were never reported to the AOD. Over the course of July 17 and 18, she became nonambulatory, incontinent, and nonverbal; she fell numerous times, cried or whined frequently. The AOD was not contacted until the night of July 18 and was only told that Ms. Rose was refusing to eat and appeared weak. The AOD was not contacted later when Ms. Rose experienced several episodes of vomiting black fluid, a clear sign of internal bleeding.
- Are direct care staff proficient in conducting assessments of clients' physical status (i.e., temperature, pulse, respiration, blood pressure, input/output, etc.)? And do they know when to conduct the assessments so that objective data concerning clients' well-being or changes in such can be reported to administrative or medical backup? In Ms. Rose's case, direct care staff reported their subjective impressions that she looked weak and was eating little, but they did not conduct basic assessments which would have yielded more objective data on Ms. Rose's deteriorating condition; nor did the AOD instruct them to do so.
- Are administrators on call qualified in interpreting the objective data reported to them concerning the physical status of clients? Do they have ready access to medical personnel for consultation or to arrange for prompt and more thorough professional examination of clients? And if medical staff are deployed to conduct an assessment of a client, are there safeguards in place to ensure that the assessment was thorough and appropriate, given the client's reported symptomatology? In Ms. Rose's case, a nurse was sent to the residence; however, despite reports indicative of abdominal distress, the nurse neglected to conduct a full examination and focused only on the possibility of injuries resulting from a recent fall. This oversight was not detected by administrative personnel.
- Finally, are direct care staff trained in summoning external emergency medical assistance, and are they encouraged to "err on the side of safety" and to call for assistance when the situation is "questionable"? Nearly three hours elapsed between the time of Ms. Rose's first episode of vomiting black fluid and her arrival at the hospital, because staff first debated whether to call for an ambulance, and then erred in summoning help by giving the wrong address.

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.

AdditionalNotes

In the Matter of Matthew Sweet:

Cautionary Notes on Swimming Activities

Case #3

Introduction

Summertime. . . and the living is easy. Schools close, vacations are planned, and all—both young and old—hop in the car and take to the great outdoors to picnic, to play, to relax. It should be no different for persons with disabilities. And, fortunately, for many, it is not.

However, for care providers of persons with significant disabilities, summertime's activities and pleasures present increased risks and demand heightened vigilance. . . the living is not easy, as demonstrated in the case of Matthew Sweet.¹ Unfortunately, each summer the Commission examines similar tragedies: a group of clients and staff embarks for a day of sun and surf, and one of the individuals drowns.

Matthew Sweet spent most of his 39 years in a succession of large state-run institutions. In the spring of his final year, he moved to a ten-bed community residence.

Diagnosed as having mild to moderate mental retardation and a schizo-affective disorder, Mr. Sweet was described as a sociable person. He was verbal and ambulatory, but prone to periodic temper tantrums and episodes of self-abuse which staff managed through redirection or hands-on behavioral intervention. He required psychotropic medications for behavior management purposes; but medically, Mr. Sweet had no major problems and required no ongoing interventions.

Overall, during the last year of life, including his last three months in a community residence, Mr. Sweet seemed to be doing well: he participated fully in programs with reduced incidents of maladaptive behavior; related well to staff and peers, particularly in the community residential setting; and experienced no major health crises.

Events Preceding Death

One hot summer day, staff of Mr. Sweet's community residence and staff of another residence operated by the same agency planned an outing at a nearby public park. The plans included a picnic, followed by swimming at the park's riverside beach.

Folding chairs, blankets, picnic lunches and refreshments were loaded into the vans. And 16 clients, including Mr. Sweet and five staff, set off for a summer's day of fun, arriving at the park in late morning.

Following lunch and a half-hour's rest period in the wooded picnic area, the entourage repaired to the roped-in beach, setting up their "gathering point" (blankets and chairs) near a lifeguard's stand, paces from the water's edge. A hot July weekend day, the beach was crowded with other bathers and staffed with a full complement of lifeguards.

Several clients in the group were competent swimmers. Others, like Mr. Sweet, were not. Based on past aquatic assessments, Mr. Sweet enjoyed water activities and displayed no sense of panic or discomfort in the water. He could place his face under water and hold his breath for ten seconds, but he couldn't swim unless provided staff's hands-on assistance. Typically, he enjoyed wading in shallow water, splashing others, and being splashed.

Upon arrival at the beach, a staff member walked into the water to establish its depth; five clients, including Mr. Sweet, joined him in the waist-deep area. For the next hour or so, Mr. Sweet was described as wading, splashing water, sitting in the shallow area, interacting with staff and other bathers, and generally having a good time.

Although there were no formal staff-to-client supervisory assignments, staff reported that, during this time, they all took turns in the water, on the beach near the lifeguard stand, or chaperoning clients to the rest room area. With the exception of two clients who did not wish to swim, all the clients spent time in the water, coming and going between their blankets and the water as they wished.

¹ A pseudonym.

Shortly before 2:00 p.m., Mr. Sweet indicated he needed to go to the bathroom and was escorted there by one staff member. Upon his return to the gathering point near the lifeguard stand, staff announced that it would soon be time to return home and that anyone wishing to take a last dip should do so now. Several clients, including Mr. Sweet, went into the water. Apparently, no staff accompanied them. Staff accounts as to when Mr. Sweet was last seen entering or playing in the water range from 2:02 p.m. to 2:08 p.m. At 2:15 p.m., however, as staff were assisting clients dry off and getting ready to leave, Mr. Sweet was noted to be missing.

While one staff member escorted clients back to the vehicles, the others mounted a search, combing the beach, shallow water, picnic and public rest areas—with no success.

At approximately 2:30 p.m., a lifeguard, informed by a young swimmer that he had seen a body lying on the bottom of the river, recovered Mr. Sweet's body. It was found in nine feet of water within the roped-in area. Residence staff were approaching the lifeguard's stand to report Mr. Sweet's disappearance when his body was recovered.

An autopsy indicated Mr. Sweet had drowned.

Lessons Learned

What started out to be a day of fun and relaxation, turned out to be a tragedy for Mr. Sweet, his peers, and the staff entrusted with his care.

In this case, like so many others seen by the Commission, the death was not the result of staff negligence. Attentive to clients' needs and desires, staff planned an outing mirroring the summertime activities of most nondisabled persons: a picnic and swim at the local public park. Attentive also to the special needs of their charges, staff took care to set up their "beachhead" at the foot of a lifeguard stand within the roped-in beach area, entered the water first to assess its depth, and took turns—albeit on an informal basis—wading in the water with nonswimmers, standing on the beach supervising clients who did not wish to swim, and escorting clients to the rest room. And, when Mr. Sweet was determined to be missing, within 7–13 minutes of last being seen, staff immediately began a search.

Could Mr. Sweet's drowning have been prevented? Could the risks of his accidental death have been reduced? The results of various investigations into his death suggest yes.

The investigations found that:

- Mr. Sweet's agency had no formal policies regarding client supervision during community swimming activities. In the absence of guidelines, well-intentioned staff did their best, but their best was not good enough. In a matter of minutes, while unable to swim and left alone in the water with no one watching, Mr. Sweet drowned.
- Valuable time was lost when Mr. Sweet was discovered missing and staff conducted a search, on their own, without notifying proper authorities. Lifeguards informed investigators that, had they been informed of a missing individual (last seen in the water), a coordinated, professional water search would have commenced immediately, thus increasing the chances of a timely and successful discovery and rescue.

Subsequently, the agency developed policies on community swimming activities. In doing so, the issues it considered, which other agencies should consider as they plan for summer activities, were:

- The swimming abilities of individual clients vary. Are the staff involved in swim activities sufficiently aware of the individuals' differing capabilities?
- Are staff-to-client ratios, generally, and staff-to-client supervisory assignments, specifically, consistent with the swimming abilities of the individuals?
- Should nonswimmers be allowed to enter the water without either a personal flotation device or an assigned staff person?
- Can the safety of individuals who are swimmers be further assured by pairing them into buddy systems and offering these clients instruction on the responsibilities of "being a buddy"?

- When staff need to be relieved of part of their supervisory duties even temporarily—e.g., to escort one of their assigned clients to a bathroom or to assist another dry off—how can other staff be alerted and assist in maintaining an appropriate level of supervision?
- Are all staff aware of the importance of *immediately* notifying lifeguards of emergencies or the need for assistance?

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 Mildred Thomas:

A Case of Untimely Medical Attention and a Sister's Plea

Case #4

Background

Mildred Thomas¹ was a 37-year-old resident of a community-based Intermediate Care Facility (ICF) in upstate New York. She had lived at home with her family until the age of 12 and then lived in several institutional settings until she moved to the community-based ICF. Severely retarded, Mildred was ambulatory, verbal, and somewhat independent in ADL (Activity of Daily Living) skills. She did, however, exhibit maladaptive behaviors—including wandering from program, crying when she “didn’t get her way,” and engaging in self-abuse and property destruction. She was under the care of a psychiatrist, who prescribed psychotropic medications to control these behaviors. Healthwise, however, Mildred suffered no major problems.

After several years, Mildred’s maladaptive behaviors escalated, and her psychiatrist changed her medications, with little effect. Notes in the house log indicated that Mildred’s head banging had created a hole in her bedroom wall, large enough to expose a steel beam. For the next several days it was noted that Mildred was up all night and screaming night and day, to the point that she was hoarse and could barely talk. Although there was an order for Tylenol “for a possible cold,” there was no evidence that Mildred was examined by the agency nurse, nor was there any indication of the symptoms which prompted this order.

Nurse Contacts

On the following evening, after dinner, Mildred experienced bouts of vomiting and diarrhea. She was also trying to scream, but her voice was too faint. An agency nurse was contacted by phone who instructed staff to give Mildred Tylenol, spray her throat with Chloraseptic, and monitor her. The nurse also reportedly instructed staff “not to bother her again” (the nurse later claimed she was only kidding). As the evening progressed, Mildred continued to vomit, and at approximately 11:00 p.m. she had what appeared to be a seizure, which was significant, since she did not have a seizure disorder. At least one staff person at this time voiced concern that Mildred might be dying.

Staff again contacted the nurse by phone and reported that Mildred had had a seizure. Staff noted that Mildred was having difficulty sitting up straight and was “breathing hard”; she also did not respond to her name or to questions. Although facility policy requires that clients with no seizure history be brought to an emergency room if they experience a seizure, the nurse ordered that Mildred be “monitored” closely, without describing what was meant by “monitoring.” (Most of the dialogue between house staff and the nurse was not documented in records.)

Oncoming night-shift staff registered concern over Mildred’s condition, but were informed of the contacts with the nurse and her orders to monitor Mildred. Throughout the night no vital signs were taken. Although the nurse claimed that she instructed staff on how to take vital signs, staff reported they had never received such training. Reportedly, Mildred—who was placed on a couch in the living room for easier observation—was periodically checked during the night and was said to be sleeping.

When day-shift staff arrived for duty the next morning, they found Mildred breathing hard and saw a dark stain on the couch under her mouth and face. They were informed by night staff that Mildred had been like this all night, and they then went about their other duties. One day-shift worker, however, returned to check Mildred and found her not breathing; she summoned her colleague who found no pulse, and 911 was called. As these staff were not trained in CPR, CPR was not started until EMS arrived.

¹ A pseudonym.

Mildred was transported to a local hospital and admitted with a diagnosis of pneumonia. The emergency room record indicated that she had been without vital signs for at least a half hour. Although a pulse returned after treatment in the emergency room, Mildred expired shortly thereafter. The cause of death, after autopsy and discussion between the Commission's Medical Review Board and local Medical Examiner, was determined to be pneumonia.

Questions and Issues for Residential Care Providers

The circumstances of Mildred's death have forced the involved agency to confront and address—through staff counselling and training, and policy revisions and other activities—questions and issues which all residential care providers should ponder as they consider whether a case like Mildred's could occur in their facilities:

- When clients (particularly those whose ability to articulate physical maladies is compromised due to their limited cognitive or verbal skills) demonstrate an increase in maladaptive behaviors, are reasonable steps taken to rule out underlying medical causes for the clients' unrest? In this case, for almost two days prior to her death, Mildred had difficulty sleeping and screamed incessantly to the point of being hoarse or faint of voice.
- Does the agency have clear and universally understood policies delineating when clients experiencing signs or symptoms of acute illness should be examined by agency nursing personnel, by a doctor, or transferred to a local emergency room for medical evaluation? In this case, the nurse violated a clear agency policy, which calls for the transfer of clients experiencing a first-time seizure episode to the local hospital; also, compounding the error of not ordering the client's transfer, the nurse failed to conduct a personal assessment of a client who was obviously in acute distress.
- Do the agency's policies empower frontline direct care staff to seek additional advice and assistance when they encounter a situation in which the orders they receive violate either facility policy or the dictates of common sense? In Mildred's case, not only did the nurse's instructions—which were blindly followed—violate agency policy, but staff had a gut, and prophetically true, impression that she might be dying; although concerned, these staff—from shift to shift—sought no second opinion; their concerns were apparently, and erroneously, calmed by the advice of a nurse who never examined the acutely ill client.
- Finally, does the agency ensure that its direct-care staff, who are entrusted with the lives and well-being of clients, have the necessary training and ability to carry out this weighty responsibility? Are they well versed in monitoring vital signs, performing CPR and summoning emergency medical assistance or second opinion or supervisory assistance in times of trouble?

While Mildred's case demonstrated problems in the area of documentation, which all agencies routinely struggle with and endeavor to improve, these pale in comparison to the problems evidenced in terms of staff judgments and skills and agency policies—the real issues which stood between timely medical care and Mildred's death. We hope that Mildred's case will present the opportunity for agencies to reflect upon their own performance in these critical areas.

A Sister's Plea

Following the Commission's investigation, Ms. Thomas's sister wrote to the Commission. The following is excerpted from her letter, which appeared in *Quality of Care* (the newsletter of the Commission), Issue 54, Nov-Dec 1992, p. 9.

Dear Editor:

I am writing for many reasons. One reason is to make sure that others who have relatives in facilities are aware of their rights in regards to their relatives. Another reason is a selfish one on my part, but I'm hoping it will help to ease my guilt on the matter. A day does not go by when I don't think of my sister and the tragic and inhuman way she was let to die. In the two years prior to my sister's death, the facility where my sister lived steadily started going downhill from what I'd known it to be. Our mom visited weekly. I visited with her once

a month or more. We visited on weekends. On weekends, I know there is usually less staff and not much activity, but it was different. It was beginning to seem that the residents were considered more of a bother or a nuisance and were being ignored quite often.

When we visited, three days before her death, she seemed to have a terrible cold—or so we were told. She couldn't talk, was very agitated and really wasn't aware we were there. I called back that evening; they told me she was going to see the doctor to be sure everything was okay.

I should have insisted she be taken to the hospital or should have taken her myself. What could I do—would the hospital have accepted her if I brought her in? I trusted they would take care of it. I must tell you that after her death, we learned that she didn't have a cold. She couldn't talk because she had spent the last two days in her room screaming and banging her head.

She was defenseless and at the mercy of others.

This letter won't mean anything unless you remember it and use it as an example. Know your rights and even overstep them, if you have to. Don't trust that the proper medical attentions are being given. Don't trust that they are being properly cared for. Protect your loved one—don't take it for granted that everything will be okay.

Sincerely,
"Mildred's" Sister

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 Jacob Fine:
Complications Following Surgery
Go Unresolved
Case #5

Background

Jacob Fine¹ was 36 years old. Diagnosed as having cerebral palsy with spastic quadriplegia and profound mental retardation, Jacob spent most of his early years in a large state institution. When he was 23, Mr. Fine was placed in a small group home where he lived with several other developmentally disabled adults. He also began attending a day program in the neighborhood.

Although nonverbal, Mr. Fine was able to express his likes and dislikes through facial expressions, certain vocalizations, and physical responses to staff questions. As he needed assistance or supervision in almost all activities of daily living, training activities—both at home and in day program—focused on improving Mr. Fine's basic self-care abilities, such as toothbrushing, washing himself, etc.

Although able to ambulate short distances with a walker, Mr. Fine required the use of a wheelchair most of the time. He was also incontinent. As such, monitoring and maintaining his skin integrity was a major treatment objective. Monitoring Mr. Fine's nutritional status was also a component of his treatment plan. At 5'1" and weighing between 100 and 110 lbs. Mr. Fine required a 3,000-calorie diet and several snacks daily to maintain an ideal body weight. Since he had difficulty chewing food due to missing teeth, Mr. Fine required a "chopped" solid diet. He was, however, capable of feeding himself with little difficulty, if provided special adaptive equipment.

Medically, over the years Mr. Fine seemed to enjoy good health. Suffering from hypothyroidism, he received Synthroid on an ongoing basis, but required no other medications except for periodic antibiotics when he experienced bouts of upper respiratory infections and conjunctivitis, to which he was prone. The results of Mr. Fine's last annual physical examination (three months before death) were within normal limits.

Events Preceding Death

One day, staff of Mr. Fine's residence noticed that his eye appeared red. They arranged for an ophthalmological consult which indicated that Mr. Fine had a corneal ulcer² which required surgical repair.

Surgery was done under general anesthesia with no ill effects noted. Weeks later, Mr. Fine returned to the hospital where the sutures were removed under general anesthesia on an outpatient basis. The next day, Mr. Fine visited his ophthalmologist who gave him a "clean bill of health" and informed staff that Mr. Fine could return to day program. He never did.

Later that day, Mr. Fine was found to be gagging, as if he was about to vomit, which in time he did. It was also noted that Mr. Fine, who had gone without solid food since the day before undergoing general anesthesia for suture removal, was refusing to eat.

The agency nurse visited the residence, assessed Mr. Fine's vital signs, which were normal, and conferred with the ophthalmologist. The physician indicated that the reduced appetite and gagging may be the side effects of the general anesthesia, which can cause throat soreness and/or decreased gastric mobility, and should dissipate in time. The nurse advised staff to have Mr. Fine drink plenty of fluids.

The next day, Mr. Fine again refused to eat solid foods. He ate some ice cream and started to gag, but did not vomit. The agency nurse recorded his vital signs, which were normal, and arranged that Mr. Fine be given high-protein fluids. This was the last time she saw Mr. Fine.

¹ A Pseudonym.

² Corneal ulcers are caused by infection following a trauma or corneal foreign body. They are also complications of herpes simplex, conjunctivitis, or other infections. The etiology of Mr. Fine's ulcer was not determined.

Over the next three days, residence staff continued to record that Mr. Fine refused solid foods, although he did drink fluids and on one or two occasions had some ice cream and pudding. He also had episodes of vomiting or gagging. On one shift, staff noted that Mr. Fine was restless and "moaning and groaning most of the night." There are no notes by staff concerning his well-being during the next 24 hours. However, on the following day, Mr. Fine was recorded as still refusing solid food; he did drink fluids, ate some pudding, and did not vomit or gag.

The next morning, the sixth day following suture removal, Jacob Fine was found unresponsive in his bed. He was transported to a local emergency room and pronounced dead. Due to religious reasons, no autopsy was conducted, and the death was attributed to natural, but undetermined, causes.

Unanswered Questions

There are many unanswered questions concerning Mr. Fine's final week, chief among them is what caused his death? In the absence of an autopsy, this will never be known. Equally mysterious is Mr. Fine's clinical condition before death.

For more than one week, Mr. Fine went without regular food—accepting only fluids or, occasionally, ice cream or pudding. He also experienced bouts of vomiting and gagging, indicative of abdominal distress. At times, staff diligently recorded his food refusals, vomiting, moaning, groaning, etc; at other times, there were no staff entries, for periods of up to 24 hours.

Although a nurse was alerted to Mr. Fine's condition shortly after his return from the hospital, she saw him only twice—on the first two postoperative days—and assessed only his vital signs. She did not conduct a full physical/nursing evaluation, including abdominal assessment. Nor did she instruct staff to conduct objective assessments of Mr. Fine's condition, or changes in such over time, by monitoring his vital signs (i.e., pulse, respiration, temperature, and blood pressure) and measuring and recording his input/output (i.e., how much fluid and foods he was consuming and how much he was voiding).

And although the ophthalmologist was contacted when Mr. Fine first experienced symptoms of discomfort, he did not feel it necessary to examine the patient, as he felt Mr. Fine was experiencing side effects from anesthesia which would soon dissipate. But as time went on and Mr. Fine's discomfort persisted, to the point of moaning and groaning at least one entire shift, neither the nurse, the ophthalmologist, nor Mr. Fine's regular internist were requested to examine him.

During the last week of his life, there was something clearly wrong with Mr. Fine, but there was no forthright and persistent attempt made to find the cause.

Lessons Learned

The case of Mr. Fine illustrates, once again, the extra care that staff must take to: monitor the health status of developmentally disabled individuals (particularly those who are nonverbal); attend to cues of possible physical distress (e.g., changes in appetite, behavior, level of activity); and conduct or arrange for comprehensive assessments to identify or rule out medical conditions which may be triggering changes in the individual's baseline behavior/activities.

In Mr. Fine's case, the community residence agency reported that in the past Mr. Fine had experienced episodes of eating difficulties—including gagging, vomiting, refusing solid food—which would resolve. (It should be noted, however, medical, nutritional, and nursing assessments for Mr. Fine for the past two years made no mention of these purported intermittent eating difficulties; in fact, they report a healthy appetite and no problems with eating.)

This reported past history, as well as the report from the ophthalmologist that Mr. Fine may be experiencing temporary side effects from anesthesia, apparently conspired to lull staff into a false sense of confidence that "all will be well," leading to lapses in monitoring and no further action as days progressed and Mr. Fine's condition persisted.

The lessons learned by the agency, in the wake of Mr. Fine's death, and incorporated into its policies and procedures are:

- Nurses called on behalf of ill clients should conduct and document full assessments.
- Before surgery, agency nurses should provide the surgeon with a complete medical history, including issues or problems other than those being addressed in surgery, such as: other medical conditions, medications, eating and voiding habits, etc.
- After surgery and hospital discharge: vital signs and input/output should be monitored three times daily; nurses should conduct a full physical examination within 72 hours; and the patient should be examined by the surgeon or the agency physician within one week.
- Additionally, if a problem arises during recovery which is unrelated to surgical care (e.g., GI problems following eye surgery), the patient should be seen by both his internist, as soon as possible, and the surgeon.

It is hoped that the lessons learned by Mr. Fine's agency will prompt others to reflect upon their own operations. Might staff be lulled into a sense of confidence that "all will be well," or do adequate procedures exist to ensure vigilant staff monitoring and follow-up when clients exhibit behaviors which may suggest medical problems?

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 Tai Sung Park:

A Case of Logistical Flaws Undermining Transition From Inpatient to Outpatient Care

Case #6

History and Inpatient Admission

Last summer, Tai Sung Park,¹ a 72-year-old oriental gentleman, was admitted to a psychiatric unit of a metropolitan area hospital. It was his first psychiatric hospitalization and was precipitated when he attempted suicide by throwing himself into a river.

Rescued by police and brought to the hospital, Mr. Park claimed he wanted to die and was "not needed in this world." Through an interpreter, Mr. Park explained that several months earlier his wife had died, and nine days later he lost his job; he feared he was a burden on his son, daughter-in-law and their children, with whom he was now living.

Mr. Park also reported that in the months prior to his suicide attempt, he had seen a private therapist who prescribed medications, but he stopped taking the medications. In the following weeks, he stated, he could not sleep, lost weight and thought often of death.

Physical assessments, upon admission, indicated no major medical problems. And a mental status examination revealed that Mr. Park was well oriented and coherent, but suffering from a major depression. Family members were consulted during Mr. Park's assessments and indicated their belief that he should be hospitalized. They also informed staff that they wanted to care for Mr. Park when he was ready for discharge.

Hospital Course

Mr. Park's treatment plan called for him to be kept on a schedule of regular observations for suicidal behavior and the initiation of antidepressant medication therapy. It also called for Mr. Park's involvement in individual verbal therapy and activity sessions with peers, and for ongoing consultations with family members.

During the first week of hospitalization, Mr. Park was plagued by sleep disturbances and thoughts of suicide, although he made no gestures. During the second week of hospitalization, Mr. Park's sleep and appetite improved. And, in private sessions, he stated that although he was sad over his wife's death, his suicide attempt was a "big mistake" about which he was ashamed. He also spoke of the very supportive role his son had played and indicated his desire to return to his son's home upon discharge.

As Mr. Park expressed no thoughts of wanting to die, special suicide observations were discontinued, and he participated in regular ward activities with no untoward events and socialized with Asian staff and patients.

During his third week in the hospital, Mr. Park was noted to be in good spirits and requesting discharge. Family members were consulted and were offered the option of an adult home facility placement for Mr. Park, but they indicated their desire for him to return to their home, which was also his desire.

Discharge and Aftercare

Arrangements were made for Mr. Park to attend a hospital-affiliated outpatient clinic whose staff, by virtue of their own heritage and training, were skilled in treating Asian patients. After three weeks in the hospital, Mr. Park was discharged to live with his son and his family; he was given an appointment for an intake session at the outpatient clinic at 1:00 p.m. ten days later. His family indicated that they would ensure that he kept the appointment, and Mr. Park promised to keep the appointment and take his medication, Sinequan, 50 mg h.s.

Although Mr. Park was given a specific outpatient appointment, no information concerning Mr. Park's history or inpatient care was transmitted from inpatient to outpatient staff.

As he was instructed, Mr. Park arrived at the clinic at the appointed time for his first outpatient session. The clinic's regular receptionist was out that day and a temporary receptionist was filling in. The therapist whom Mr. Park was to see was also out at the time,

¹ A pseudonym.

attending a training session, so the substitute receptionist informed Mr. Park that he could not be seen and rescheduled him to return to the clinic in two weeks.

Mr. Park never returned to the clinic. Twenty-three days after his release from inpatient status, and one day before he was to return to the clinic for the rescheduled appointment, Mr. Park hanged himself in his son's home.

Little is known about Mr. Park's final days. Did he take his medications? What was his reaction to being turned away from the clinic to which he had been referred? Did he again perceive himself as being a burden on his family? Was his son equipped to provide him the level of supervision and support he may have required? Did thoughts of death again resume and sap him of his will to live? Did new stressors in his life emerge? Whereas Mr. Park's nearly every move and mood change were monitored by psychiatrists, therapists, nurses and other staff during the three weeks he was hospitalized after his first suicide attempt, he was not seen once by mental health professionals in the three weeks following his hospital discharge.

Discussion

The case of Mr. Park illustrates the window of vulnerability individuals face as they transition from inpatient to outpatient service, and the care which must be exercised in assisting them in that transition. It also demonstrates how thoughtful discharge planning can be undermined by logistical flaws.

During his hospital stay, inpatient staff paid considerable attention to Mr. Park's needs: he was maintained on special levels of observation; his medications, mental status and progress in individual therapy and group activities were closely monitored by clinicians; and his family—his primary support—was immediately and consistently included by inpatient staff in planning his course of care. As Mr. Park's status improved and inpatient staff determined he was ready for discharge, they were also diligent in planning aftercare services tailored to his needs: both Mr. Park and his family were consulted about residential options, with all parties agreeing to Mr. Park's return home; arrangements were made for Mr. Park to attend an outpatient clinic which specialized in the treatment of Asian patients; and Mr. Park was given a specific appointment date and time for his first outpatient appointment.

Logistical flaws, however, undermined hospital staff's carefully tailored plans for Mr. Park's transition to outpatient service. Mr. Park reported for his first outpatient appointment. But his assigned therapist was not available, due to a scheduling conflict, nor was the clinic's regular receptionist. A temporary receptionist, without consulting with other clinicians, informed Mr. Park to come back in two weeks. And not having had received any clinical information from the inpatient unit, outpatient staff, unaware of Mr. Park's suicidal history, hospital course and life stressors (including his sense of being a burden on his family with whom he was now living) made no attempt to arrange for a more immediate assessment of Mr. Park's status and his linkage with services.

Lessons Learned

Following investigations into Mr. Park's death, the hospital initiated a number of corrective actions to ensure better communication between inpatient and outpatient units and follow up on patients who are not seen in their clinic as scheduled. Specifically, *prior to the discharge* of a patient, the inpatient therapist must now speak with the outpatient therapist to whom the patient is being referred and forward the clinic certain inpatient records, including admission notes, treatment plans, the discharge summary and aftercare support plan. In these conversations and referral packets, the inpatient therapist must identify any patient deemed to be "at high risk," which includes patients admitted for suicide attempts, self-destructive behaviors or violent episodes, or patients with significant histories or risk factors for self- or other-injurious behaviors. Patients considered "high-risk" are to be given priority for initial outpatient appointments so that they do not have to wait ten days for their first session. The appointment scheduling system was also revised to flag "high-risk patients" and more readily identify patients who, for whatever reason, are not seen as scheduled.

The facility's plan of correction also called for inpatient staff to be notified of any patient who is not seen for the initial outpatient appointment. And inpatient staff, who have a therapeutic alliance with such patients, are expected to contact the patient to assess the

situation and reschedule the appointment. If the patient cannot be reached by phone and the history suggests that the patient might be at risk, a mobile crisis team will be deployed to visit the patient. Outpatient staff are responsible for similar follow-up on patients who make initial contact with the outpatient program, but miss subsequent appointments.

In reviewing the case of Mr. Park, staff of other facilities should consider whether their institution has adequate safeguards to ensure the successful transition of patients from inpatient to outpatient status. Do facility policies promote the laudable aspects of Mr. Park's discharge planning?

- Are families consulted and involved in total treatment planning, including plans for the patient's discharge and aftercare?
- Are the unique needs of patients, be they cultural (as in this case) or otherwise, addressed in discharge planning?
- Are patients, upon release, given specific appointments with aftercare providers?

And do facility policies advance the lessons learned by Mr. Park's hospital in the wake of his death?

- Are outpatient providers given sufficient clinical information, both in writing and verbally, concerning patients prior to their discharge to outpatient care?
- Are high-risk patients identified and given priority in scheduling aftercare appointments to ensure their linkage with outpatient services?
- Is there an adequate system in place for identifying patients who miss outpatient appointments and for following up on them, even through home visits, if need be?

Are all staff, both inpatient and outpatient, aware of the facility's policies and their obligations concerning the successful transition of inpatients to outpatient care?

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 Julian Webber:

Delayed Response to Decompensation

Results in Tragedy

Case #7

Introduction

Julian Webber¹ was born and raised in upstate New York. Diagnosed as having chronic paranoid schizophrenia, Mr. Webber's psychiatric difficulties dated back at least to the late 1970s when, at age 18, he was first admitted to a psychiatric hospital; he had overdosed on psychotropic medications prescribed for his father who was under treatment for schizophrenia.

At the time of this hospitalization, Mr. Webber was experiencing delusions of being persecuted. He also reported that he was depressed: his older brother, with whom he was very close, had left the family home, joined the service and married.

After a several-month hospital stay, Mr. Webber was discharged to live with his family.

Over the next decade, Mr. Webber—denying he had a problem—was noncompliant with outpatient treatment and was admitted to psychiatric facilities on numerous occasions. Exacerbations of paranoid delusions—of people attempting to poison or control him—coupled with social isolation and threats or acts of violence, often aimed at his family, prompted the hospitalizations. Also, during this period, Mr. Webber's older brother shot himself to death, an event which severely troubled Mr. Webber.

Need for Supervised Living

By the late 1980s, given Mr. Webber's need for daily supervision and the stress on his parents who eventually separated, it was determined that a community residence placement was indicated. Mr. Webber was agreeable to the plan and he was placed in a group home sponsored by a private agency.

Over the next couple of years, Mr. Webber reportedly did well and participated in the household's routines. He continued to deny that he had a serious mental illness and was wary of any "formal" mental health counselling programs. He also denied the need for psychotropic medications; however, he usually complied with his medication regimen, which was monitored by staff.

Although he was plagued by continuing paranoid delusions of being x-rayed or poisoned by other people, for the most part the delusions were kept in check through medications and did not substantially interfere with his daily activities. On those occasions when it appeared that his mental status was deteriorating, as evidenced by increased social isolation or agitation, adjustments in the medication regimen usually stabilized the situation.

During one period of decompensation, however, Mr. Webber assaulted and seriously injured a fellow resident of the group home with a knife. This prompted his involuntary admission to a local hospital and, after nearly two months, transfer to a state psychiatric center for long-term care.

A New Placement

Mr. Webber remained in the psychiatric center for six months, during which time he was stabilized on Stelazine 40 mg daily. Although he continued to have some paranoid thoughts, he did not act on them and was less agitated. He enrolled in the center's work-for-pay program, working in the facility's laundry room, and was quite productive and thrifty, saving his earnings.

By the fall, Mr. Webber was deemed ready for discharge, but in need of continued supervision. As his serious assault on another client precluded Mr. Webber's return to that residence, Mr. Webber was placed in a state-operated residence near the psychiatric center.

The discharge plan called for Mr. Webber to continue working in the psychiatric center's laundry facility, and transportation arrangements were made for him to commute to and from work. He was enrolled in a local clinic for at least medication management purposes, as he

¹ A pseudonym.

refused any further clinical services such as verbal therapy/counseling; and residence staff—most of whom were aides without professional clinical or medical training—were to monitor his medication compliance, daily activities, and mental status, and report any changes to the psychiatrist at the clinic.

Initially, Mr. Webber adjusted to life in the new residence quite well. Tending to shy away from staff, he socialized with other residents. He continued to work at the psychiatric center. Using his earnings, he fixed up his old pickup truck and brought it back to the residence to use on weekends to visit his parents. Although judged capable of self-administering medications, Mr. Webber preferred that staff store and administer his medications, even though he denied that he needed them. On occasion, residence staff questioned whether Mr. Webber was truly ingesting all his medications as he had a history of adeptly “cheeking” and later discarding them; but overall, they believed he “took most of his medications most of the time.”

Minor Crises

During the first several months in the residence, Mr. Webber experienced two short-term exacerbations of his psychotic symptomatology, evidenced by isolation, increased verbalizations of paranoid delusions, agitated behavior, and threats against staff.

On the first occasion, Mr. Webber was immediately brought to his clinic psychiatrist who increased his Stelazine to 60 mg daily and advised staff that involuntary hospitalization may be in order, if medication adjustment did not work. Over the next two weeks, residence staff monitored his condition and spoke frequently with the psychiatrist, reporting that the medication change had been effective.

Three months later, Mr. Webber was brought to an emergency room of a local hospital as he was agitated and threatening staff. After a period of observation during which he evidenced no threatening or agitated behavior, Mr. Webber was released with no change in his medication regimen or overall care plan.

In the following months, Mr. Webber continued work in the laundry and participated in household routines. He was seen regularly by his clinic psychiatrist who maintained him on Stelazine 60 mg daily and noted that while Mr. Webber was doing well, he had no insight regarding his illness nor any desire for therapy.

The Final Crisis

Approximately one year after moving to the residence, Mr. Webber again began to decompensate. He abruptly quit his job at the laundry, and over the next nine days residence staff noted that he appeared to be responding to hallucinations and paranoid ideation: expressing thoughts of persecution, refusing to eat with other residents, becoming angry with others for no apparent reason, and isolating himself in his room.

At one point he was overheard telling another resident that this time of year was difficult for him as it was when his brother committed suicide and another member of his family died. The night this was overheard, staff noted that Mr. Webber appeared even more withdrawn.

Late on the afternoon of the ninth day, residence staff decided Mr. Webber's psychiatrist should be contacted the following morning to request an immediate appointment.

Shortly after this decision was made, Mr. Webber left the residence without telling staff and drove to his father's house. (This was unusual as Mr. Webber did not drive in the dark.) Mr. Webber's father called the residence to report his son was at his home and would stay there for several days. Residence staff, after speaking with the father, spoke with Mr. Webber and advised him to return to the residence, at least for his medications; he declined, saying he would return to the residence the next morning after he got a haircut.

The next morning, residence staff alerted Mr. Webber's psychiatrist to his several-day period of decompensation, his elopement the evening before, and his planned return to the residence that morning. The psychiatrist agreed to see Mr. Webber immediately upon his return to the residence.

However, Mr. Webber did not return. A “Missing Persons” report was filed by the residence, and police investigations indicated on that day Mr. Webber withdrew funds from his bank and purchased a rifle and ammunition. Two days later his truck was found in a

secluded area; his body was found nearby. He died of a gunshot wound to the head, as his brother had, and the death was ruled a suicide.

Lessons Learned

The investigation into Mr. Webber's death surfaced issues which the psychiatric center operating the residence acted to resolve. It also presented lessons from which other community residence agencies can learn.

Community residences are not intended to provide clinical services, and their staff, by and large, are not trained clinicians. It is expected that community residence clients receive their clinical services from community-based professionals and that residence staff ensure linkage with such professionals and advocate for clients when additional services are needed.

When Mr. Webber began showing signs of decompensation—beginning with precipitously quitting his job—residence staff, without consulting with his psychiatrist, made a *de facto* clinical decision that Mr. Webber was not a danger to himself or others. They believed the changes in Mr. Webber's behavior signaled another of his cycles of decompensation and improvement which they had seen him experience twice before with no deleterious outcome. After nine days of observing his deterioration, they determined the psychiatrist should be contacted; but again judging that there was no imminent danger, they decided the contact could wait until the next morning.

Even after Mr. Webber eloped that evening, drove to his father's home, and refused to return for medications, staff made no attempt to bring him his medications, visit and assess his situation with his father, or call clinicians for assistance in assessing and responding to the entire scenario: Mr. Webber's nine-day period of decompensation, his report of this being a "difficult time" due to the anniversaries of family members' deaths, and the unusual events of that day, i.e., his elopement, driving in the dark, and wanting to stay with his mentally disabled father.

Recognizing that community residences do not provide clinical care, yet their staff are the first to notice changes in clinical status which may signal the need for clinical intervention, the psychiatric center examined, as all community residence agencies should: Are residence staff sufficiently trained to notice signs of decompensation? Are staff aware of what to do when signs of decompensation are evident? Are there adequate linkages with clinical resources in the community to ensure a timely response to emergencies? Are the resources available 24 hours a day, seven days a week?

This critical self-examination following the death of Mr. Webber prompted the facility to provide additional training for staff, develop client-specific plans for medical and psychiatric emergencies, and establish linkages with community-based clinical resources which would be available if the need arises on evenings and weekends. The facility also revised its policies on clients' motor vehicles to ensure greater accountability for their use.

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 Noah Paul:

A Study in the Need for Improved Communication Concerning Individuals with Special Needs

Case #8

Background

Noah Paul¹ was born in 1916. Diagnosed as having severe mental retardation, Mr. Paul lived in State institutions most of his adult life. In the mid-1980s, however, he was placed in the family care home of Mrs. Alex.¹

Family care is one of New York's oldest community-based care programs for people with mental disabilities: natural families open up their homes and hearts to care for one or more disabled individuals who are unable to live independently but do not require the structure or more intense supervision offered in community residences or intermediate care facilities. Family care homes are "sponsored" by State-operated or -licensed mental hygiene agencies whose staff train the family care provider and visit the home monthly to assess conditions, monitor client needs, and offer the provider additional training or assistance, if needed. Staff of the sponsoring agency also provide case management and advocacy services on behalf of the family care client.

Mrs. Alex's home was sponsored by the developmental center in which Mr. Paul had resided for decades.

Mr. Paul moved into Mrs. Alex's home with two other developmentally disabled gentlemen and over the next ten years did well. He attended a day program for developmentally disabled senior citizens on a regular basis and participated in and enjoyed its routine activities as well as its special events, such as field trips and vacations.

The most recent psychological assessment indicated that Mr. Paul was a friendly, good-humored individual who spoke in one or two word phrases. It was noted that he tried hard to please others and responded well, with broad smiles, to praise, encouragement, and compliments on a job well done.

According to the psychological assessment and Mrs. Alex, Mr. Paul was independent in most self-care tasks; however, he needed assistance with personal hygiene activities and supervision during meals, as he had a tendency to eat too fast. Although ambulatory and able to get around his household, Mr. Paul could not travel independently in his neighborhood or to his senior citizen day program.

Overall, the psychological assessment indicated Mr. Paul functioned in the severe range of mental retardation, and that there had been a slight regression in his functional abilities since his last complete triennial assessment; the regression, it was felt, was due to the aging process. (Mr. Paul was 77 years old at the time of this most recent assessment.)

Despite his advanced years, Mr. Paul enjoyed good health and suffered no major, life-threatening illnesses during his years in family care. However, during his most recent annual physical examination, it was discovered that Mr. Paul had an elevated prostate-specific antigen, indicative of possible prostate cancer. Appropriate consents were secured to perform a biopsy and further treatment if cancer was diagnosed.

Hospital Admission

While preoperative tests (e.g., blood work, EKG, etc.) were being scheduled on an outpatient basis, Mrs. Alex noticed that Mr. Paul's right leg was swollen and red. She took Mr. Paul to the emergency room of a local hospital where he was examined and diagnosed as having an infection; Mr. Paul had picked at his leg causing a sore. He was placed on oral antibiotics, and Mrs. Alex was advised to bring Mr. Paul back to the hospital if the swelling and redness did not resolve, or worsened. Several days later she escorted Mr. Paul back to the emergency room as the swelling and redness had worsened, and he now had several leg ulcers.

¹ All names are pseudonyms.

Mr. Paul was admitted to the hospital with a diagnosis of cellulitis of the right leg. He was started on intravenous antibiotics and skin soaks.

According to Mrs. Alex, at the time of Mr. Paul's admission she informed nursing staff of his need for supervision while eating as he had a tendency to eat too fast. There is no record of this conversation or Mr. Paul's special need in the hospital's nursing notes. A note entered by a nutritionist on Mr. Paul's second day in the hospital indicated that he needed "assistance with feeding"; but reportedly this indicated that his food should be cut for him, not that he should be supervised while eating.

It was decided that while Mr. Paul was hospitalized, he would undergo the remaining preoperative tests and the planned prostate biopsy.

However, after the noon meal was served on his third hospital day, a nurse's aide found Mr. Paul in bed unresponsive with no vital signs. A code was called and the responding team found that Mr. Paul's oral cavity was full of food.

Mr. Paul was successfully resuscitated and transferred to the Intensive Care Unit where it was determined that he choked on food, aspirating some. He was placed on a respirator and treated for aspiration pneumonia. He also developed congestive heart failure. Mr. Paul's sister was consulted and with her consent he was placed on a Do Not Resuscitate status. On the seventh hospital day, Mr. Paul expired.

Lessons Learned

Mr. Paul's death was directly related to a behavior or special need which either his caretaker did not adequately communicate to hospital personnel, or hospital staff did not sufficiently appreciate. Although he did not have a history of choking in the recent past and did not require a special diet to reduce the likelihood of choking (due to poor dentition or gag reflex), he had a tendency to hastily ingest his food unless supervised and reminded to slow down: a tendency which his caretaker felt put him at risk for choking and a behavior/special need she claims she told hospital staff about.

Individuals responsible for providing 24 hour-a-day long-term care for disabled people know their charges and their special needs far more intimately than caretakers, such as hospital staff, who may occasionally be entrusted with the well-being of the disabled person for a brief period of time and a very specific purpose, e.g., treatment of cellulitis or a prostate biopsy.

How does one ensure that hospital staff, who are understandably focused on a specific medical problem, are sufficiently aware of the total needs of the individual entrusted to their care, particularly those needs which may have serious consequences if left unattended? How does one ensure that those special needs are appropriately attended to by hospital staff? And what does one do, if they are not?

In Mr. Paul's case, his caretaker of ten years reportedly told hospital staff about his special need regarding meals; she also informed staff of the agency which sponsored her home about Mr. Paul's hospitalization. Although she received reports on Mr. Paul's medical status and relayed the information to her sponsoring agency, she did not assess whether Mr. Paul's need for supervision while eating was appropriately addressed, nor did staff of the sponsoring agency.

In response to Mr. Paul's unfortunate death, the developmental center sponsoring Mrs. Alex's family care home (and more than 70 other family care homes serving nearly 140 clients) put a process in place to assure answers to the above questions – questions which all agencies face when their clients are hospitalized or temporarily in another's custody:

- A special form, or profile, is completed on each client living in family care highlighting the individual's unique needs and special considerations in such areas as activities of daily living (including eating skills), mobility/ambulation, adaptive equipment, known allergies, behavioral issues, etc.
- Should the individual require hospitalization, a copy of the profile will be given to the hospital at the time of admission, and staff of the developmental center will be alerted to the hospitalization.

- A staff member from the developmental center's medical service will then visit the individual in the hospital to assess the overall care and attentiveness to special needs and, if needed, initiate discussions with hospital staff as to what steps will be taken to ensure special needs are met, including the assignment of one-on-one staff. The developmental center's hospital liaison staff member will maintain ongoing contact with the hospital during the course of the admission, and the developmental center's chief medical officer can be called upon if additional advocacy efforts with the hospital are indicated.

These protocols are worthy of consideration by all agencies which struggle with assuring that the individuals they serve receive optimal care while in the temporary custody of other service providers.

Ironically, the developmental center sponsoring Mrs. Alex's family care home had these procedures in place for the community-based group homes and intermediate care facilities it developed in the last 20 years. It had not, however, applied the protocols to the family care modality, which has existed in New York State since the 1930s. This in itself is an object lesson on the care agencies must take to continually revisit and review how well they communicate with hospitals and advocate on behalf of individuals entrusted to another party's care, even temporarily.

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 Frieda Fleischman:

A Study of the Interface Between Adult Homes and Mental Health Services

Case #9

Background

Frieda Fleischman¹ was born and raised in the New York City area. There she worked as an artist, married, and reared two daughters with her husband.

Ms. Fleischman's psychiatric difficulties began in the mid-1970s, when she was in her early 40s, and the family was beset with medical, financial and other difficulties. Her husband required open-heart surgery. The same year, she nearly died following complications arising from gynecological surgery. The family's finances were strained by these twin medical events, and Ms. Fleischman became increasingly withdrawn and depressed.

In 1977, Ms. Fleischman required psychiatric hospitalization when she threatened to commit suicide by jumping into a nearby lake; she reported having hallucinations. Following hospitalization she and her husband divorced, and she eventually lost contact with her daughters who were in their 20s. Subsequent hospitalizations occurred when Ms. Fleischman stopped taking psychotropic medications and was found confused, depressed and wandering the streets. At various times she was assigned the diagnoses of undifferentiated schizophrenia and major depression, recurrent.

Homes for Adults

In 1982, following her last psychiatric hospitalization, Ms. Fleischman was placed in a Home for Adults (HFA). Certified by the Department of Social Services, HFAs are supervised residential facilities serving individuals who require some supervision or assistance in daily activities, but not as intense a level of care as would be provided in more richly and professionally staffed residential programs—such as community residences for individuals with mental illness certified by the Office of Mental Health or Department of Health-certified nursing homes for medically frail people. Whereas, for example, an HFA is required to provide a staff-to-client ratio of at least 1 to 40, the minimal staffing ratio for supervised community residences is 1 to 14 and even richer for nursing homes.

Although HFAs are expected to monitor residents' health and mental health needs, they are not expected to provide direct services to address these needs; such services are to be rendered by community-based professionals. And, an HFA is expected to have an agreement with an outpatient mental health service provider, if at least 25 percent of its residents (or 25 residents, whichever is less) suffer mental illness. The nearly 200-bed HFA in which Ms. Fleischman lived had such an agreement with a local psychiatric center which provided individual and group therapy and medication management services for Ms. Fleischman and the home's other residents.

Life in the Residence

Over the next 11 years following her 1982 placement, Ms. Fleischman did well in the HFA. Records describe her as being articulate, sociable, very capable in tending to her own daily needs, and helpful to other residents who were less capable in these matters than she.

Medically, Ms. Fleischman experienced some problems over the years as she aged into her sixties: she was diagnosed as having chronic obstructive pulmonary disease, glaucoma, rheumatoid arthritis, and diabetes, and required daily medications for these conditions.

Psychiatrically, Ms. Fleischman remained fairly stable. Although she experienced periodic exacerbations of her depressive disorder coupled with psychotic symptoms (hallucinations and delusions), she was quickly stabilized through adjustments to her psychotropic

¹ A pseudonym.

medication regimen, which consisted of a neuroleptic and an antidepressant, and she did not require psychiatric hospitalization. Ms. Fleischman often attributed her periodic depressive episodes to her medical maladies.

Events Preceding Death

In the fall of her 64th year, Ms. Fleischman was hospitalized for pneumonia. After nearly two weeks of treatment, she returned to the HFA. Over the next few weeks, residence staff and her outpatient therapist noticed changes in Ms. Fleischman's behavior and demeanor. She was withdrawn and isolative, ate irregularly and seemed depressed. When questioned by her therapist, she denied being sad or depressed; she reported that she was "recovering" from her recent illness. However, one month after the hospital discharge, Ms. Fleischman confided to the therapist that she was sad; she reported that she was hearing voices telling her to hurt someone and that she didn't want to hurt anyone, or herself.

The therapist immediately increased Ms. Fleischman's psychotropic medications and, over the next month, saw her almost daily. The therapist noted that Ms. Fleischman began socializing with peers more spontaneously and frequently. She also began eating more regularly. And although she still appeared to be a little depressed, Ms. Fleischman reported that the voices were no longer troubling her and that she felt much better.

One month after the medication adjustment, however, Ms. Fleischman did something out of character. In the middle of a cold winter night, she attempted to leave the residence wearing only a housedress and no shoes. (She was usually asleep at this hour and always dressed appropriately when awake.) Residence staff stopped her and she stated that she wanted to go out for cigarettes. Residence staff gave her their own cigarettes, watched her smoke, and then escorted her to her bedroom. Although they recorded this unusual behavior in the facility's logbook, they did not notify the residence's administrator or the outpatient mental health staff, even though these parties are on-call 24 hours a day.

The next morning, Ms. Fleischman's unusual behavior continued. When given her morning medications (which she took religiously), she threw them in the garbage, stated, "What's the use of living," and walked away. Again, no supervisory residential staff or mental health staff were consulted about this.

When day-shift residential staff reported for duty, they were informed of Ms. Fleischman's unusual behaviors during the previous shift. They conducted a search for Ms. Fleischman, who could not be found, and notified the police. At this point, residence supervisors and mental health staff were also alerted. Several hours later, Ms. Fleischman's body was found on a beach several blocks from the residence. An autopsy indicated that she drowned.

Lessons Learned

Over 10,000 individuals with serious mental illnesses live in Homes for Adults (HFA) across New York State. Many, like Ms. Fleischman, are sustained in the community for years without the need for inpatient psychiatric hospitalization through assistance in daily living activities offered by the paraprofessional staff of the HFAs and the clinical supports provided by mental health service agencies with which HFAs have service agreements.

The sustenance of these individuals requires open and clear communication between HFA and mental health service staff, and an understanding among all staff about their respective roles and the special needs of the residents.

Investigations into Ms. Fleischman's death indicated that such communication did not occur in the hours before her death and that not all staff were clear about their roles and responsibilities. Residence staff, although concerned about Ms. Fleischman's unusual behaviors the night before and on the morning of her death, did not immediately notify supervisors or the mental health team, who could have arranged for or conducted a professional assessment of her status and need for increased supervision, services, or even hospitalization. Even her statement, "What's the use of living," did not prompt staff to immediately alert others to their concerns or to provide Ms. Fleischman more supervision. Rather, they waited for the day shift to arrive. In the meantime, Ms. Fleischman disappeared, entered the ocean, and died. It also appeared that the outpatient mental health service did not sufficiently educate residence staff on matters which should trigger their notification immediately and how to do so on a 24-hour-a-day basis.

Following Ms. Fleischman's death, residence staff and mental health outpatient staff took steps to remedy the breaches in communication and understanding of respective roles illustrated by the circumstances surrounding her death.

- Outpatient staff reiterated their availability on a 24-hour-a-day basis to respond to crisis situations or offer advice to residence staff when troublesome situations arise.
- Residence staff were reminded of their duty to notify residential supervisors, as well as mental health officials, and the *means to do so*, when residents appear to exhibit unusual behaviors.
- *Most importantly*, the residence, with the input of the mental health outpatient program, provided training to the residence's paraprofessional staff on signs and symptoms of possible decompensation on the part of residents which should trigger immediate notification to residence supervisors and the mental health team. The residence and outpatient mental health providers are also exploring avenues for continual and joint training programs on residents' needs.

The case of Ms. Fleischman underscores the importance of outpatient programs serving HFAs, and the HFAs themselves, to ask:

- Are residence staff sufficiently aware of signs that a resident may be decompensating?
- Should additional training in this regard be offered, and how can both residence managers and outpatient clinicians share in this responsibility?
- If a resident appears to be decompensating, is there a clearly communicated means for residence staff to consult with outpatient clinicians, particularly during non-business hours, such as evenings and weekends?
- Are all residence staff aware of their duty to report noteworthy changes in residents' behavior or status to their supervisors and outpatient staff, and are they aware of the means for doing so?

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 Nancy Bauer:

Untrained Staff + Lack of Readiness = the Formula for Disaster

Case #10

Mealtime can be one of the most pleasant experiences of the day, a chance to soothe the pangs of hunger, to enjoy the aroma, taste and texture of a well-prepared dish, and to relax in the company of others sharing the trials and joys the day will bring or has already wrought. For individuals with severe disabilities, and even for some without, it also presents a time of risk, as the case of Nancy Bauer¹ illustrates.

Background

Ms. Bauer was born in upstate New York, the product of a full-term, uncomplicated pregnancy. Although she was born with no known abnormalities, Ms. Bauer's parents noticed that her achievement of major developmental milestones—such as mobility and language development—was significantly delayed. In time, she was diagnosed as suffering from Phenylketonuria² which had resulted in mental retardation.

Ms. Bauer was admitted to a large state developmental center when she was 13 years old and her parents realized that they could no longer provide the level of care and supervision she required. Her diagnosis was profound mental retardation secondary to her metabolic disorder.

A New Home

Ms. Bauer lived in state developmental centers until the early 1980s when, at age 33, she was placed in a 30-bed community residential facility near her parents' home. The facility, operated by a not-for-profit agency, is divided into residential units, each home to ten individuals. During waking hours, when residents are not at their day programs, each unit is staffed by a manager and three direct care staff.

Over the next 12 years, Ms. Bauer lived without serious incident in the residence. Profoundly retarded and nonverbal, she required assistance in nearly all aspects of daily living, from bathing, to dressing, to eating. One of her more serious problems was self-abuse—slapping or banging her head. For her protection, she wore a helmet; there was also a behavioral plan in place to address this problem through staff intervention, redirection and reinforcement.

Health-wise, Ms. Bauer suffered no major medical problems. However, she was prone to weight loss: Given her difficulties with self-feeding and poor dentition, she was prescribed a soft diet (i.e., meats or other solids were to be ground) with extra portions. Staff were to sit next to Ms. Bauer to assist her at mealtime and to monitor her, as Ms. Bauer sometimes grabbed others' food.

The Incident

One September Saturday morning, the manager for Ms. Bauer's unit was ill and did not report for work on time, leaving three direct care staff present to care for the unit's ten residents. Two of the three, Ms. Smith and Ms. Jones, had worked for the agency for only three weeks, had not completed all their training, and had minimal contact with the unit's residents; the third, Ms. Quincy, had worked for the agency for only six months.

The morning got off to its usual start with the three staff waking residents, assisting them in their morning routines (e.g., showering, dressing, etc.) and ushering them to the dining room for breakfast.

¹ A Pseudonym.

² Phenylketonuria (PKU) is a metabolic disorder which results in the body's inability to convert phenylalanine to tyrosine. Consequently, phenylalanine and its metabolites accumulate in the blood, causing mental retardation.

As one individual—prone to behavioral difficulties—needed extra assistance with his shower, the more “seasoned” team member, Ms. Quincy, remained with him, while Ms. Smith and Ms. Jones escorted the other nine residents to breakfast, which consisted of pancakes and sausage links.

Once in the dining/kitchen area, Ms. Smith had difficulty using the processor which ground food for individuals on soft diets. She went to another unit to grind the solid food, leaving Ms. Jones, who had never worked on the unit before, to care for the nine residents in the dining room.

Unaware of the special dietary needs of the nine residents, Ms. Jones served Ms. Bauer pancakes and sausage links. Ms. Jones sat next to Ms. Bauer and cut her pancakes and sausage into bite-size pieces. As she was preparing to assist Ms. Bauer feed herself, another resident asked for more juice and Ms. Jones went to the kitchen to get some, leaving the nine residents alone.

Upon return from the kitchen, Ms. Jones sat next to Ms. Bauer who immediately stood up and ran to the living room, sat on the couch, and put her head down. At this point Ms. Smith returned from the other unit with the ground food portions. She noticed that Ms. Bauer did not look right; she was pale. Ms. Jones reported to Ms. Smith that Ms. Bauer did not want to eat and had run to the living room. Ms. Smith then went to the neighboring unit to report that Ms. Bauer did not look well. Neither staff assessed Ms. Bauer for vital signs.

Emergency Medical Care

Staff from the neighboring unit accompanied Ms. Smith back to Ms. Bauer’s unit and found Ms. Bauer blue, without vital signs. Told that Ms. Bauer had not eaten, no one attempted the Heimlich maneuver. Instead, the responding staff initiated CPR. (Neither Ms. Smith nor Ms. Jones had been trained in CPR or the Heimlich maneuver.) As staff were working on Ms. Bauer, a code was called; Ms. Quincy – who had finished showering a resident – came upon the scene and assisted in the resuscitative efforts, as did other staff who responded to the code; and the local emergency medical service squad was summoned.

Staff working on Ms. Bauer called for oxygen; however, the oxygen tank brought to the scene was empty. The emergency kit brought to the scene also lacked CPR masks (protective devices to prevent the exchange of bodily fluids during CPR).

Paramedics arrived at the scene about ten minutes after they were summoned; they were delayed as they had difficulty locating the residence, which was “off the beaten track,” and were given no special directions.

While attempting to intubate Ms. Bauer, EMS personnel removed a 1/2- to 3/4- inch piece of sausage link from her mouth/throat. Ms. Bauer was then successfully intubated and, while receiving Advanced Cardiac Life Support in transit to a hospital, regained a pulse and respirations.

Ms. Bauer, however, never regained consciousness and died several days later due to cerebral anoxia as a result of food aspiration. The coroner classified the death as an accident.

Lessons Learned

Many lessons were learned from the death of Ms. Bauer.

Recognizing that two new staff still in training were left to care for nine of the unit’s residents, the facility realigned staffing patterns to ensure that at no time will more than one “trainee” be assigned to a unit each shift.

Additionally, the minimal staffing level for mealtime was increased. At the time of Ms. Bauer’s choking incident, it was expected that at least one staff member be present in the dining room during meals. It was not a violation of policy for Ms. Smith to leave Ms. Jones alone in the dining room with nine residents while she went to another unit to grind some food. The incident, however, taught the agency how easily a lone staffperson’s attention can be diverted, and how quickly tragedy can occur during that period. While alone with the nine clients, Ms. Jones’ supervision of the residents was momentarily diverted when she went to the kitchen to get juice for one client who was asking for more. During this brief interlude, Ms. Bauer evidently attempted to ingest, but aspirated, a sausage piece—which was not seen by staff. Minimal staffing levels for mealtime were augmented. It is now expected that two staff be present in each unit’s dining room for meals.

Recognizing that the two new staff on the scene had not yet been trained in some of the most basic elements of first aid (i.e., the Heimlich maneuver and CPR), the facility revised its orientation and training schedule to ensure that trainees receive such training prior to assuming direct care responsibilities.

In response to problems with emergency medical equipment availability, the facility also instituted monthly checks of the availability and working order of emergency equipment.

And, finally, the agency provided the local ambulance squad written directions on how to get to the facility.

It took a preventable tragedy to teach an agency harsh lessons on many issues which perhaps it took for granted. The tragedy of Ms. Bauer's death presents an opportunity for other agencies and their staff to ensure that they too are not taking similar issues for granted.

- New employees/trainees should be deployed to wards/living units to receive direct, hands-on experience, but do agencies' staff deployment practices assure that new employees assigned to direct care duties are surrounded by more seasoned, experienced staff who can monitor, guide and assist the novice?
- Recognizing the opportunities, as well as risks, associated with mealtime, are agencies' staffing patterns at these critical periods sufficient to promote skill development and socialization, and prevent untoward incidents?
- Do agencies' orientation and training programs assure that new employees receive appropriate training in critical life/safety and first aid matters before they are deployed to receive hands-on experience in the care of dependent persons?
- Do agencies have regular schedules for inspecting emergency medical equipment to ensure it is readily available and operational at all times? Is the available equipment sufficient to respond to the emergent needs of individuals, and are staff trained in its use?
- And, for those program sites which may be "off the beaten track" in rural areas, or hidden in a maze of streets and high-rise buildings in urban ones, do agencies have clear and precise directions to the program location which can be shared in advance with local community emergency response teams and reported to response teams in the initial calls made when emergencies occur?

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 Cynthia Ashley:

Death Follows Prescription Difficulties

Case #11

Background

Cynthia Ashley¹ was 48 years old when she jumped to her death from her apartment building. Born and raised in New York City, Ms. Ashley had a normal childhood. The older of two children, she lived at home and got along well with her parents and younger sister. She did well in school, earned two graduate degrees in the human service field, and secured a professional job.

She married when she was in her mid-twenties, and by the age of 31, she and her husband had a son and moved to the suburbs. She left her job to raise their child.

Ms. Ashley's psychiatric difficulties began when she became depressed in her mid-30s. She attributed the depression to the fact that her mother, with whom she was close, was having medical problems; her father, with whom she had also been close, died of cancer several years before this.

For approximately the next three years Ms. Ashley was treated by a private psychiatrist. Treatment consisted of verbal and medication therapies. During this time Ms. Ashley resumed work with a human service agency. Feeling better, Ms. Ashley terminated her relationship with the private therapist.

The First Hospitalization

Several years later, however, Ms. Ashley began having delusions that her former therapist was harassing her via prank phone calls and visiting neighbors in her apartment building, telling them the confidential content of her therapy sessions. After tracing telephone calls and speaking with neighbors, family members tried to convince Ms. Ashley that her fears were unfounded.

Around her 48th birthday, Ms. Ashley told her family she was afraid of "losing control and killing" her former therapist. Her husband facilitated her voluntary admission to the psychiatric service of a local hospital.

At the time of admission she was delusional and experiencing active homicidal ideation. She was started on Haldol 2 mg daily and involved in individual and group therapy. Her homicidal thoughts quickly dissipated, and by week two of the hospitalization she was acknowledging that her concerns about the former therapist may not have had a factual foundation. During her second week of hospitalization, she destroyed a file which she had maintained, and constantly carried with her, on her former therapist's "history" of harassment.

After 17 days in the hospital, Ms. Ashley was deemed ready for discharge. Both she and her husband were agreeable to an aftercare plan which entailed her continuation of Haldol 2 mg and regular therapy sessions at a local clinic, which she and her husband chose.

Ms. Ashley returned to work upon discharge, but failed to keep regular clinic appointments. She also stopped taking medications because, as she later reported, she felt better.

The Second Hospitalization

Approximately eight weeks after discharge, Ms. Ashley attempted suicide by ingesting a bottle of aspirin. Discovered by family members, Ms. Ashley was taken to another local hospital and admitted to the Intensive Care Unit. Over the next 24 hours her medical condition was stabilized and she was transferred to psychiatry.

Upon admission to the psychiatric service, Ms. Ashley denied current suicidal ideation but admitted that, at the time of the attempt, she had intended to kill herself. She claimed that "too many things had come together at once"; she further explained that she had just recently been reprimanded by her employer over performance issues, which distressed her, and that her only

¹ A pseudonym.

son was completing high school and would soon move from home for college. She reported that prior to her suicide attempt she had suffered from a decreased appetite, sleep disturbances, and poor concentration. During initial evaluations, Ms. Ashley appeared paranoid and guarded, with flat affect.

She, and family members, reported her recent prior hospitalization at a different facility and subsequent noncompliance with aftercare plans following that admission. Information from that hospital was obtained. From these sources, a fairly complete picture of Ms. Ashley's history emerged, including: her academic achievements, job successes, and difficulties; her close and supportive family, and concerns over her only child leaving home; her period of depression ten years earlier, involvement in treatment, and her subsequent paranoid delusions about the therapist; and her recent hospitalization for delusional thinking, and noncompliance with planned aftercare services, including medication (Haldol) and verbal therapy.

Ms. Ashley was assigned the diagnosis of major depression and, given her history, delusional disorder. She was started on Prozac 20 mg and Haldol 2 mg, which had been prescribed during her previous hospitalization.

In addition to medication therapy to address her depressive and paranoid symptoms, Ms. Ashley's treatment plan called for her involvement in individual and group therapy. She also was asked to identify personal treatment goals and strategies she would use to attain them. As requested, on a weekly basis she submitted written evaluations of her progress toward her goals which included: increasing her self-esteem and level of assertiveness (by thinking about her good qualities and speaking to others in an assertive, rather than aggressive manner); reducing her isolation from others (by writing letters and participating in groups); and articulating/understanding the reason for her hospitalization (by speaking in group sessions).

Over the next three weeks, Ms. Ashley became less withdrawn and paranoid; she participated in therapy sessions – at first hesitantly, but in time more openly, talking about the importance of medication compliance; and she began socializing with her peers more frequently. She denied any suicidal ideation and expressed remorse over the aspirin incident.

During her second week of hospitalization, Ms. Ashley developed tremors, thought to be a side effect of the Haldol. The Haldol was discontinued, and she was prescribed Risperidone 2 mg daily, a recently marketed antipsychotic medication which reportedly has fewer side effects than older-generation neuroleptics.

During the hospitalization, Ms. Ashley enjoyed frequent visits from family members. She also went on two home visits which reportedly went well. Ms. Ashley spoke often of her desire to return home and resume her role as wife and mother.

The Discharge

Given Ms. Ashley's improvement, desire to return home, absence of suicidal ideation, and successful home visits, discharge planning was set in motion. Several meetings were held with the family and Ms. Ashley, during which it was agreed that Ms. Ashley would be discharged home with a plan to attend the hospital's outpatient clinic.

Three weeks after admission, Ms. Ashley was discharged with prescriptions for Prozac 20 mg and Risperidone 2 mg daily and an outpatient appointment scheduled for the next week.

When Ms. Ashley reported for her scheduled outpatient clinic, she told the psychiatrist that she had not been taking Risperidone—her antipsychotic medication—as she could not fill the prescription because the pharmacies she visited did not carry it. During his evaluation, the psychiatrist noted that the patient seemed paranoid and very guarded. Although in his narrative progress note the psychiatrist recorded that Ms. Ashley had no suicidal ideation, on the hospital's standardized Self Injury Inventory (a "yes/no" check-off sheet), the psychiatrist checked off "yes" for a question concerning the patient's self-destructive acts/suicidal ideation.

At the end of this session, Ms. Ashley was given a new prescription for Risperidone and an appointment for her next clinic visit.

Ms. Ashley left the clinic and returned to her apartment building. She went to the roof and jumped to her death. A maintenance man in the building who had a chance to interact with Ms. Ashley prior to her death recalled that she stated she could not get her medication.

Lessons Learned

There were many laudable aspects to Ms. Ashley's most recent inpatient treatment: the development of a comprehensive history; the active involvement of the patient in developing treatment goals and strategies and even having the patient record progress notes on her headway toward the goals; careful monitoring for medication side effects; the judicious use of home visits to evaluate Ms. Ashley's out-of-hospital experiences; and the inclusion of her family in treatment and discharge practices.

Her case, however, presented other, less desirable, aspects from which others may learn.

Following discharge, Ms. Ashley was unable to fill her prescription for a recently marketed antipsychotic medication. She reported this to the hospital's outpatient clinic. At the time, she had not taken the medication for a week and appeared guarded and paranoid. The record presents two conflicting statements concerning the possibility of suicidal ideation at that time. On interview, however, the psychiatrist said she had no suicidal ideation and that his positive indication of suicidal ideation on the Self Injury Inventory was intended to reflect a history of suicidal ideation in the past; the form did not allow for clear distinction between past and current ideation. The psychiatrist released her from the clinic with a new prescription for the same medication without addressing the reported problem of where she would fill it.

Following the investigation into Ms. Ashley's death, the hospital initiated corrective actions which other facilities may wish to consider.

First, policies were changed to better ensure that patients receive prescribed medications upon discharge. At the time of discharge, patients are instructed to call the prescribing psychiatrist if they encounter difficulties filling the prescription upon release. The psychiatrist is expected to call the patient's preferred pharmacy and attempt to resolve the problem. If this fails, the psychiatrist is expected to call a private pharmacy located in the hospital which will fill the prescription.

The hospital also substantially modified its Self Injury Inventory to distinguish remote, recent, or current attempts or ideation of self-harm and the nature of the harmful behavior/ideation.

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 Renee Curtin:

Relaxed Vigilance Undercuts

Standards of Care

Case #12

Background

At approximately 5:00 a.m. on New Year's Day, the family care home¹ of Mr. and Mrs. Newell² erupted in flames. Awakened by the sound of their barking dog and ringing alarms, the Newells smelled smoke, sent their son to a neighbor's home to summon help, then attempted to rescue the two mentally retarded individuals who resided in their home. One of the individuals, Sara,² immediately responded to the screams of "fire" and fled the house. Renee Curtin,² however, did not.

Mr. Newell attempted to go upstairs to Ms. Curtin's bedroom, but was forced back by flames and heavy smoke. In his rescue attempt, he fell from the staircase and was injured. Mrs. Newell likewise attempted a rescue, but was turned back by flames. She could hear Ms. Curtin calling for help and shouted for her to crawl from her room to the stairs and safety, but soon Ms. Curtin ceased calling for help. Meanwhile, a neighbor attempted to reach Ms. Curtin's room using a ladder from outside, but he too was driven back by smoke and flames.

Soon after, firefighters arrived at the scene. Battling the blaze, they found Ms. Curtin lifeless in bed, with second- and third- degree burns to her face, trunk and extremities. Ms. Curtin was transported to a local hospital where she was pronounced dead.

Renee Curtin was a 31-year-old woman diagnosed as functioning within the mild range of mental retardation. Verbal, ambulatory, and independent in most self-care skills, Ms. Curtin spent most of her years in state institutions. At the age of 27, Ms. Curtin moved into the family care home of Mr. and Mrs. Newell, where she lived with their two children—one of whom was not at home at the time of the fire—and one other mentally retarded resident, Sara. Ms. Curtin had no major medical problems and on weekdays attended a sheltered workshop.

The Newell home reportedly was visited and inspected on a monthly basis by staff of its sponsoring agency, the local state developmental center in which Ms. Curtin formerly resided. Ms. Curtin and Sara were found well cared for during the reported visits. And the home usually was found to be neat, clean, and in compliance with most of the standards governing the operations of family care homes, such as requirements concerning physical plant and safety issues, the inclusion of residents into the everyday routine of family life, and arranging for needed medical or other essential services. The Newells, however, did have some periodic problems satisfying certain documentation requirements, such as maintaining records on residents' personal allowance accounts.

Fire Investigation Results

State and local fire investigators conducted an inquiry into the source of the blaze which claimed Ms. Curtin's life and destroyed the Newell home. It was determined that the fire originated in a laundry room beneath Ms. Curtin's bedroom and quickly spread through the century-old, wood-frame house.

While battling the blaze, fire fighters found a kerosene spaceheater fully engulfed in flames within the laundry room.

Mrs. Newell admitted to arson investigators that she had used the kerosene heater one or two days before the fire to thaw out clothes which were frozen in a washer in the unheated laundry room. But she claimed that the heater had run out of fuel and was not in use at the

¹ Family care is a residential care modality in which one or several mentally disabled individuals live with a surrogate family. While the residents leave their home to attend school or special programs during the day, it is expected that at other times they be woven into the fabric of everyday life with their host family.

² A Pseudonym.

time of the fire. An independent consultant examined the severely damaged kerosene heater and concluded that it was impossible to determine if the heater was in use at the time of the fire; the heater was too severely damaged.

Burn patterns and the ruling out of other possible causes, however, led arson investigators to conclude that the kerosene heater was the most probable cause of the conflagration. The fire and Ms. Curtin's death were ruled to be accidental.

The Aftermath

With the destruction of the Newell home, the sponsoring agency informed Mr. and Mrs. Newell that they could no longer be family care providers. Sara was moved to a new home and continued to attend her day program, and the case manager responsible for monitoring Ms. Curtin's family care placement continued family care monitoring duties for her other homes. Business went on as usual.

Commission Investigation

Several facts, however, puzzled Commission investigators. The use of portable space heaters as the *sole* source of heat in rooms is prohibited by family care regulations, and they can be used as temporary supplemental sources of heat only with the special permission of the Commissioner after it has been determined that the safety and well-being of residents will not be compromised.

Such permission was never granted in the Newell case. Additionally, monthly inspection reports filed by the case manager for the past year or more indicated that no space heaters were used in the home. As protocol required, these monthly inspection reports were countersigned by Mrs. Newell, suggesting her awareness of the standards of care and the prohibition against space heaters. Yet Mrs. Newell, while denying the heater was in use on New Year's Day, admitted that the family had used the space heater a day or two before the fire.

During her interview with Commission staff, Mrs. Newell maintained that she was unaware of the prohibitions against space heaters in family care homes. When questioned about the monthly inspection reports which indicated that space heaters were not used and were signed by her, Mrs. Newell disclosed that the case manager did *not* make monthly visits, and at times up to six months would pass between visits.

She further indicated that when the case manager did visit, she would bring a batch of monthly inspection forms which together they signed. Additionally, Mrs. Newell showed the Commission investigator a hand-written note by the case manager given to Mrs. Newell after the fire. It instructed Mrs. Newell on what to tell investigators should they inquire about the case manager's performance. Among the points covered were: she visited the home regularly on an announced and unannounced basis; she periodically inspected most of the rooms; she never observed a space heater.

The case manager, who had already been interviewed by the Commission and her agency, was reinterviewed by the Commission. In tears, she confessed that she did not visit the home regularly; she maintained, though, that no more than three months lapsed between visits. She also admitted to not regularly touring all the areas of the home, falsifying inspection reports, and instructing Mrs. Newell what to say should anyone inquire. She indicated that she did not believe monthly visits were necessary as it was her impression that this was a well-maintained home. She also stated that supervisors did not ask her whether she visited, or what she saw when she visited; it was her impression that as long as she "filed paperwork" with her superiors on a regular basis, they were happy.

Finally, the case manager acknowledged that this was not an isolated incident. She had been doing it for years, with other family care homes.

The Commission shared these revelations with the agency which sponsored the Newell home and employed the case manager. The case manager, facing disciplinary action for her serious misconduct and negligence, resigned.

The agency promptly resurveyed the homes on the case manager's workload to ensure they were in compliance with standards. It also instituted some additional internal controls to reduce the likelihood of similar situations in the future:

- The monthly inspection form was amended to include comments about whether clients were home at the time of the visit and what they were actually doing.

- In addition to reviewing these monthly reports, supervisory staff now are expected to meet with case managers monthly to discuss the status of each home monitored by the case manager.
- Supervisory staff are expected to visit each home at least annually, in addition to the case manager's monthly home visits and other visits associated with the certification process.
- Random audits of case managers' site visit schedules, site visit reports, travel vouchers, billings and statements of official vehicle use are being conducted monthly on a sample basis to ensure visits occurred as planned/required.

Discussion

Despite Mrs. Newell's denials, state arson investigators believe the kerosene space heater was in use at the time of the New Year's Day fire and was the most probable cause of the blaze which claimed Ms. Curtin's life.

Would this tragedy have been avoided had Ms. Curtin's case manager visited the home with the frequency required? Would she have noticed a prohibited heater in use, or nearby ready for use? By carefully reviewing with Mrs. Newell the items on the inspection report, would she have imparted a sense of the dangerousness surrounding the use of kerosene space heaters? No one knows.

What is clear, though, is that the case manager did not view monthly visits and the issues she was expected to review as important. By missing monthly visits and then bringing stacks of inspection reports for providers to quickly sign, indicating that visits had occurred and critical standards of care reviewed, the case manager also communicated to providers in unspoken but not uncertain terms that the standards they are expected to uphold are not important. These are ingredients for disaster.

As the locus of care for individuals with disabilities shifts from institutions, with all services located under one roof, to community-based settings, where people are dependent on a variety of service providers, there has been an increased reliance on case managers to coordinate and monitor the quality of services. But how does one monitor the "monitors," the case managers...particularly when the nature of their work requires out-of-office field activities – often to far-flung places?

There is no one easy answer. Rigorous audits of time sheets, travel schedules, gas mileage, etc. may serve the purpose of "catching" an errant employee, if he or she is lax enough to leave such a trail of evidence; however, it comes at the cost of demoralizing a valued and needed work force largely committed to its job, but perhaps not cognizant of the importance of certain expectations, uncertain about priorities, or befuddled by competing priorities.

The case of Renee Curtin offers some lessons for programs struggling with this issue and those charged with delivering and supervising case management services:

- Are case managers sufficiently aware of the reasons behind the duties they are expected to perform, the importance of the issues they are expected to monitor, and the potentially devastating impact of failures to monitor?
- Are supervisory structures in place which prompt regular discussion of case managers' activities and findings with supervisory staff, or has supervision been reduced to a "paper chase"?
- Do case managers have a forum in which to discuss and resolve competing priorities?
- Do supervisory staff periodically conduct field work themselves to monitor the caliber of case management services?
- And are the individuals receiving case management services, as well as other service providers, given opportunities to voice satisfaction or concern about the services rendered?

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 Bonnie Johnson:
*Hot Water System with Malfunctioning
Temperature Control Causes Life-
Threatening Burns*

Case #13

The Incident

Bonnie Johnson¹ is a 63-year-old woman who moved to her community residence in 1986. She has mild mental retardation and, prior to her injuries, required only minimal supervision with cooking, cleaning and finances. She was able to shower, dress herself and organize her daily routine independently.

On a Saturday morning not long ago, Ms. Johnson entered a bathroom in the residence and took her shower. As she reported later, when she tried to turn the water off at the end of her shower, she inadvertently turned the control the wrong way and the water got too hot. Ms. Johnson backed into the far end of the shower and called for help. Another resident heard her, and summoned the Assistant Manager who found the bathroom full of steam, and Ms. Johnson standing in the shower. He turned off the water which was "very hot" and helped Ms. Johnson out of the shower. Burns were visible on her feet, thighs and breasts. She was taken to the local hospital which provided emergency treatment, and she was then transferred to a specialized burn unit at another hospital.

Diagnosed with third-degree burns over 25% of her body, Ms. Johnson required months of treatment. Her general condition has varied from critical to guarded. Six weeks after her injuries, the attending physician noted that her chances of dying were greater than her chances of living. She has had surgery for skin grafts to her legs, breasts and arms, and has had one surgical debridement to her right leg. Ms. Johnson has been on and off a respirator, and has been placed on nasogastric tube feeding because she no longer has a gag reflex. She has had multiple blood transfusions, endoscopy under general anesthesia to diagnose burn-stress-induced gastric ulcers, and multiple other treatments. She has had both pneumonia and septicemia; the septicemia persists as of this writing. The prognosis for her continued survival is uncertain.

How the Burns Were Caused

How could such serious scalding burns occur in a residence in which the maximum temperature of water in a shower was not supposed to exceed 110° Fahrenheit? The equipment in place to regulate water temperature was similar to that found in many residential facilities and included both a mixing valve supposedly set to deliver water not warmer than 110°F and a solenoid valve designed to shut off the flow of water if the temperature rose above the 110°F mark. No regular checks of the system were in place to insure that it was operating correctly and staff had not been trained to recognize signs of problems in the system. The facility's investigation, which included the first thorough examination of the water regulating system in years, revealed that the system was badly in need of repair.

After this tragedy, a plumber from an independent company found that the solenoid valve had been circumvented by pipes which diverted the flow of hot water around the solenoid valve. In addition, the mixing valve was operating erratically. When Ms. Johnson opened the hot water tap in the shower, the mixing valve delivered water hotter than 110°F, and the open bypass around the solenoid valve permitted the scalding hot water to proceed to the bathroom where Ms. Johnson was showering.

The facility's investigation was unable to determine when the bypass was installed or why it was left open. A bypass is typically installed to permit repair work to be performed on a solenoid valve without shutting off all of the hot water to the residence. Once repairs are complete, the bypass should be closed. In this circumstance, a plumber or maintenance worker may have inadvertently left the bypass open at some point in the past. Alternatively, the valve may have been tampered with by someone other than a plumber who wanted to increase the

¹ A pseudonym.

availability of hot water and did not understand the purpose of the valve and did not appreciate the risk presented by leaving it open. However it happened, the stage was set for injury when the bypass was left open.

Other Scalding Accidents

The Commission has encountered other instances in which residents of OMRDD-certified facilities have suffered scalding burns when temperature control equipment has failed. In one case, a young child in a children's center received burns to his foot which required skin grafts. The cause of this injury was a faulty pressure balancing valve which permitted hot water to pass through it without the addition of cold water. The faulty valve allowed water hot enough to cause the second-degree burns when water from the shower head dripped on the child's foot after the child care worker had turned off the shower.

In another more recent incident, a 23-year-old man with severe retardation received first-degree burns on his back and second-degree burns on his buttocks when the water temperature exceeded 110°F in the whirlpool tub used for his bath. This instance is particularly noteworthy since the residence and the plumbing was new. The agency determined that their error lay in following the advice of their contractor that mixing valves were adequate as the *sole* means of protecting residents from water hot enough to burn.

How Hot Is Too Hot?

As the chart reproduced below reveals, the severity of a burn is a function of the temperature of the water *and* the duration of the exposure *and* the condition of the skin. Children and older people, who typically have thinner skin, suffer more severe burns in a shorter time and at lower temperatures than adults. A child can suffer a third-degree burn in 124°F water in less than three minutes. Children and adults can be burned this badly in two seconds or sooner in 149°F water. These temperatures are well within the capabilities of residential hot water heaters.

It is worth noting that this chart indicates how quickly third-degree burns, the most serious burns, can occur. These burns involve extensive tissue damage and have the potential for serious disfigurement, deformities, loss of function and death. First- and second-degree burns occur even more quickly, and, when sizable areas of the body are involved, also require immediate and skillful medical treatment.

Lessons Learned

Unfortunately, as the cases above illustrate, injuries such as these can occur for a variety of reasons. No one solution or set of equipment can safeguard all residents from scald-type injuries. However, some recommendations can help program managers and administrators reduce the possibility of such injuries in their programs.

Estimated Times/Temperatures Causing a Full Thickness (3°) Burn in Children/Adults			
	Temperature	Adults	Children 0-5 years
Common	< 160°F	1 second	-
home boiler	< 149°F	2 seconds	0.5 seconds
settings	< 140°F	5 seconds	1 second
	135°F	-	4 seconds
Recommended	133°F	16 seconds	-
setting	< 130°F	35 seconds	10 seconds
	127°F	1 minute	-
	125°F	2 minutes	-
	124°F	3 minutes	-
	120°F	10 minutes	-
		skin thickness of 2.5 mm	skin thickness of 0.56 mm

* Reproduced by permission of the National Burn Victim Foundation

No system of temperature-regulating equipment, regardless how comprehensive or sophisticated, can function effectively if it is not properly maintained. As Ms. Johnson's agency learned, several low-cost steps can be taken to assure that the equipment is in good working order. These include:

- Training all direct care staff to report any instances in which the water from bath, shower or sink faucets is too hot for comfort. While individual tolerance and perceptions of temperature vary from person to person, as a general rule 110°F is not experienced as too hot to be uncomfortable.
 - Equipping every residence with a thermometer and insuring that an employee is assigned the weekly duty of checking and recording temperatures in each tub and shower when only the hot water tap is opened. A simple cooking thermometer can be used for this purpose, and can be purchased in many hardware or variety stores for under \$10. Finding water hotter than 110°F coming from a tap accessible to residents should trigger a check by maintenance workers to adjust or repair the system.
 - Scheduling regular checks of the hot water system by maintenance staff to insure that it is in good repair. Such checks should occur at least annually, or whenever residential staff note temperatures above 110°F.
 - Where a bypass of temperature control devices has been installed to facilitate repair work, the handle to open the bypass should be removed or otherwise secured in the closed position, and only authorized staff given access to open the bypass.
 - Where extra protection is desired, providers should consider installing devices at the shower head or faucet which will interrupt the flow of water when the temperature becomes hot enough to scald. Such devices, purchased for about \$15, were installed in Ms. Johnson's residence as a third check on the water temperature, even after the system was repaired.
- Many program administrators are, not surprisingly, wary of plumbing issues, feeling much more comfortable with people, not pipes. Nonetheless, the cost of ignorance, as paid by Ms. Johnson, is too high to calculate.

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 Jesse Caron:
*Lessons for Agency Administrators
and Direct Care Staff on Abuse Cover-Up*
Case#14

Background

On the day after Christmas, Jesse Caron¹ reported to his sheltered workshop, as he had for the past two years since moving from an institution to a community residence. On this day, though, something was different. Mr. Caron's left eye was black and blue and almost swollen shut; the white of the eye was completely bloodshot.

Concerned, workshop staff asked Mr. Caron what had happened. He told them a staff member from his residence punched him in the face on Christmas Eve. Workshop staff immediately called the director of Mr. Caron's residential program. The director arranged for a medical examination and commenced an investigation into the allegation of physical abuse by residence staff.

The medical examination indicated that while the area around Mr. Caron's eye was severely bruised, the eye sustained no permanent injury. Mr. Caron reported to the agency's investigator, as he had to workshop staff, that he was punched by a residential staff member. He also requested to be moved to a new residence, a request which was accommodated.

Diagnosed as having a seizure disorder and moderate mental retardation, Mr. Caron was ambulatory, verbal and self-sufficient in most activities of daily living. He was, however, prone to temper tantrums when he did not get his way. On such occasions he became verbally abusive to others or engaged in property destruction. A plan was in place to address these behaviors through redirection, escorting Mr. Caron to a quiet or "calming down" area, and with approved hands-on physical interventions by staff to prevent him from harming himself or property, if his behavior escalated. Mr. Caron, however, had no history of striking out at others. And, according to a behavioral specialist who interviewed Mr. Caron following the allegation of abuse and reviewed his clinical record, Mr. Caron had no history of making false accusations.

Initial Agency Investigation Results

According to the agency's investigation, at approximately 4:00 p.m. on Christmas Eve, Mr. Caron asked to call a friend. The request was denied by the residence manager who believed Mr. Caron might attempt, inappropriately, to invite himself to a Christmas party at a neighboring community residence.

Disappointed, Mr. Caron became verbally abusive and stormed upstairs to his bedroom, from which thumping sounds were soon heard. The residence manager asked fellow staff member, Mr. Romano, to check on Mr. Caron, who was found bouncing his basketball in his room. He appeared agitated. Mr. Romano escorted Mr. Caron downstairs to the residence's recreation room. The manager checked on Mr. Romano and Mr. Caron soon after their arrival in the rec room. Although the situation seemed under control, the manager asked the third staff member on duty, Mr. Philipson, to go to the rec room to assist Mr. Romano if he needed it.

Mr. Philipson reported that all was calm as he entered the rec room: Mr. Caron was sitting on a couch with Mr. Romano nearby. But shortly after his arrival, and while his back was turned as he worked on files, Mr. Philipson heard a scuffle. He turned to see Mr. Romano and Mr. Caron on the floor. Mr. Romano was asking Mr. Caron, "Why did you swing at me?" and the two were struggling, with Mr. Romano attempting to restrain Mr. Caron's upper body. Mr. Philipson assisted by grabbing Mr. Caron's legs. After about 10 minutes of being held face-down on the floor, Mr. Caron calmed down and staff released their grasp, allowing him to stand. It was then staff noticed his eye was somewhat swollen.

¹ All names are pseudonyms.

The residence manager was informed of the injury and contacted a nurse by phone. At her instruction, ice was applied to the injury.

Facility Investigation Conclusions

During the facility's investigation, Mr. Caron maintained he was punched by a staff member. Staff, however, denied striking Mr. Caron. Mr. Romano, who claimed that Mr. Caron took a swing at him, initially stated that Mr. Caron's face hit the rec room door knob as he was being wrestled to the floor following the attempted punch. And Mr. Philipson claimed he saw nothing, as he was busy working on files. Mr. Romano's statement, however, did not convince the facility investigator: given the layout of the room, the location of Messrs. Caron and Romano, and the testimony of the residence manager and Mr. Philipson, who stated the rec room door was closed, it was impossible for Mr. Caron to strike his face on the door knob. Furthermore, Mr. Philipson, who while not seeing anything as his back was turned, did not hear anything which sounded like a head hitting a door.

Confronted with these findings, Mr. Romano changed his story, somewhat. He told the facility investigator that it may well have been possible that in his restraint of Mr. Caron he accidentally struck him in the face.

Troubled that he lied in his initial statements about the origin of Mr. Caron's injury, the agency transferred Mr. Romano to a different residence where he could be more closely supervised. However, the agency deemed there was insufficient evidence that Mr. Caron was the victim of abuse. Based on Mr. Romano's revised statement, the agency concluded that Mr. Caron may have been accidentally struck by some part of Mr. Romano's body while being restrained.

A New Investigation

Upon receipt and review of the facility's investigation report, the Commission recommended the agency reopen its investigation, citing that:

- while Mr. Romano wavered in his version of events, Mr. Caron was steadfast in his claim he was punched by staff and had no history of making false accusations;
- staff neglected to secure appropriate medical attention for Mr. Caron as the severity of his injury became more apparent over the next two days; and
- the entire incident was precipitated by denying Mr. Caron access to a telephone, which was his right.

Things Turn Ugly

When the agency reopened its investigation, Mr. Romano again changed his story. In this version, he claimed that after Mr. Caron swung at him and was restrained to the floor, Mr. Philipson kicked Mr. Caron three to five times in the head. He also stated that when swelling around Mr. Caron's eye was noted, the residence manager told him and Mr. Philipson to report Mr. Caron had struck his face on a door knob. With this new version, police were called in on the matter.

In the ensuing investigation, Mr. Philipson denied kicking Mr. Caron; he also became more forthcoming about what he saw in the rec room "while working on files."

According to Mr. Philipson, while Mr. Caron was sitting on the couch, Mr. Romano ordered him to lie on a floor mat, which had been used as a quiet, calming-down spot. Mr. Caron refused and Mr. Romano pulled him up by the shirt. At this point, Mr. Caron swung at Mr. Romano, but missed. In reaction, according to Mr. Philipson, Mr. Romano punched Mr. Caron in the face and chest several times and both fell to the floor where a restraint was employed. Mr. Philipson assisted by holding the client's legs.

When Mr. Caron was released and his injury was noted, Mr. Romano became afraid he'd lose his job, according to Mr. Philipson. So, both staff told the residence manager what had transpired and the manager instructed them to report that Mr. Caron hit his face on a door knob.

Upon interrogation, the residence manager confessed that he fabricated the door knob story to cover for Mr. Romano, who told him he had overreacted, punched Mr. Caron, and was afraid of being fired.

Resolution

Reinterviewed, Mr. Caron maintained, as he had in all previous interviews, that he was punched by a staff member. He denied that he was kicked, as Mr. Romano had most recently alleged. But, he could not name the staff member who punched him; he could only describe the car his assailant drove. The description matched the car driven by Mr. Romano.

Subsequently, the District Attorney's Office charged Mr. Romano with assault in connection with Mr. Caron's beating. He was fired by the agency for abuse, as were the residence manager and Mr. Philipson for their complicity in covering up the abuse.

Lessons Learned

The Jesse Caron case illustrates several lessons for both agency administrators and direct care staff. The first is the care which must be taken to objectively collect, analyze and weigh evidence in client abuse cases, particularly when it appears that the only available evidence is the testimony of the victim and the prime suspect.

Throughout his ordeal, Mr. Caron maintained he was punched by a staff member. He had injuries consistent with his claim, and he had no history of fabricating stories or making false allegations. Yet he was not believed.

Instead, the agency chose to believe Mr. Romano— an employee who changed his initial "door knob" story when confronted with facts which proved it impossible. And while "buying" Mr. Romano's revised account that he may have accidentally made contact with Mr. Caron's face during the restraint, the agency clearly had reservations about Mr. Romano's veracity as evidenced by his transfer to a job where he could be watched more closely. Yet, administrators chose to believe his account over Mr. Caron's. It wasn't until external parties (the Commission and police) became involved that the truth was exposed and the agency realized it had a far more complex problem involving abuse *and* conspiracy.

No one wants to see abuse occur in their programs. Agency heads, however, must take steps to ensure that this strong desire does not obscure their vision or prejudice their objectivity in investigating allegations. Agency heads have at their disposal a powerful tool to assist in this regard: the involvement of law enforcement authorities. New York State law requires agencies to report apparent crimes to police, and certain forms of abuse, particularly physical and sexual assaults, constitute crimes. The early involvement of law enforcement authorities in abuse investigations can assist agencies in maintaining objectivity, communicate to all parties the seriousness the agency attaches to such allegations, and lead to the quick resolution of charges.

A second lesson warranting reflection is the degree to which staff will go to "help" a fellow worker. There is a special bond among direct care staff: few others are willing to do the jobs they take on, work the hours they put in, for the money they make. Their camaraderie enables them collectively to achieve what no one could do individually— provide quality care. It also provides a strong temptation to "cover" for a fellow worker who has erred.

As demonstrated by the Caron case, the worker who loses control, punches out a client and conspires with others to cover his act, may be the first person to blame his peers for his own misdeed.

Direct care staff should consider the perils to their own careers and the health and well-being of the individuals they serve when tempted to cover for abuses by their peers.

Finally, a simple request, denied by staff, triggered a chain of events: assault, serious client injury, conspiracy, the termination of three employees and the arrest of one. All, perhaps, could have been avoided had Mr. Caron been allowed to exercise his right to make a phone call.

Questions for Consideration

- Does the agency afford equal weight to the testimony of clients and staff in abuse allegations unless the scales are reasonably tipped by legitimate questions of credibility or other evidence?
- Has the agency cultivated relationships with police authorities to enlist their assistance in objectively investigating potential criminal situations and foster their understanding of the special needs of disabled persons?
- While encouraging staff to report abuse, do agency policies recognize the special, and at times difficult, role of direct care staff and provide a means for staff to safely/anonymously report abuse? Do practices communicate that the agency will respond fairly to honest mistakes to improve staff's care-giving capacity? Or do practices promote a fear of reporting?
- Are staff sufficiently aware of client rights issues, not just as spelled out in law and regulation, but as also experienced in everyday situations, such as someone wanting to use a phone, have a visitor, smoke or linger a bit longer at breakfast for a second cup of coffee? Are staff prepared to deal with conflicts over such issues without allowing them to escalate into physical altercations?

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 James Manning:

A Case of Unrealistic Supervision Expectations

Case #15

The Incident

The dayroom was full of activity as the youngsters and staff of the adolescent psychiatric unit enjoyed cookies and punch to celebrate an important occasion—one of them was going home. For James,¹ 16, the party was a welcome break in what had been a very difficult week. Several days earlier, he had been sexually assaulted on the unit by another patient. James was too psychotic to identify the perpetrator or to relate the specifics of the incident credibly. Thus, staff were not able to identify the aggressor. In an effort to protect James from future victimization, he was placed on 1:1 supervision.

The policy and procedure manual for the psychiatric service specifies that staff must “maintain close visual and physical contact with the patient” while carrying out this duty.

During the party, Raymond,¹ 14 years old, became annoyed when James came too close to him and raised his arms, perhaps shadow-boxing. Instantaneously, Raymond struck James in the face, then in the next motion threw him to the floor. James’ one-to-one staff member and other staff responded to the incident quickly, but not quick enough to prevent serious injury to James. He was unresponsive on the floor, with fixed and dilated pupils, and his extremities were spastic – all symptoms indicating neurological damage. James was immediately transferred to the medical emergency room of the hospital, and later that evening underwent surgery for evacuation of a left epidural hematoma. In time, James recovered completely.

One of the first questions that came to mind when the incident occurred was: How could this youth be assaulted into unconsciousness by a peer when he was supposed to have a staff member in close physical contact with him? The answer was clearly apparent as soon as staff assignments were examined. The staff person assigned 1:1 to James to protect him from peers was also assigned 1:1 to another male patient to protect him as well. She was near the other patient at the time of the attack on James.

Discussion

In this case, a staff member was given an assignment that was impossible to carry out. Past history with this facility indicated that the hospital had adopted the practice of assigning more than one patient on 1:1 status to a single staff member years earlier and had never abandoned the practice, because of limited resources. While program administrators are often under pressure to continually stretch limited resources, this supervision practice is a dangerous one.

- If a patient truly needs the close surveillance of 1:1 observation, this dilution of supervision places him/her at risk.
- The practice feeds on itself, encouraging misuse of enhanced supervision levels. Because physicians know that 1:1 supervision does not really mean 1:1, but rather merely more attention and increased monitoring, they more quickly put patients on 1:1 status who may not require it or may leave patients on this status longer than necessary. In either case, these practices eventually pull more resources from the mainstream group of patients, providing greater reason for physicians to put patients on 1:1 status, and the cycle continues.

Carried to their extreme, this and similar practices can make enhanced supervision status nearly meaningless.

¹ All names are pseudonyms.

Defining Supervision Expectations

- In some facilities where supervision lapses have caused similar harm to patients, the problem has been with the lack of specificity of the policy. Some policies say staff “must know the whereabouts” of each patient – giving no specifications for how often the activities of the patient should be checked. Consequently in one instance, two young boys, six and eight years old, playing in the doorway of a bedroom, engaged in sexual fondling and were moving on to oral sex before they were discovered by staff who knew their whereabouts, but were visually checking only every once in a while.
- Other policies note, for example, that staff must be within arm’s reach of the patient, except when the patient is in his/her bedroom or bathroom. There is no guidance regarding what staff should do in these exempted circumstances – maintain visual contact? stand in the doorway? stand outside the doorway? Thus, one staff member was devastated when a person on suicide watch, whom she had been conscientiously watching, cut her wrists in a bathroom stall with a piece of glass she had hidden in her sock. The staff member had been maintaining arm’s-length supervision of the young woman until she allowed the woman to enter the bathroom stall and latch it from the inside.
- In still other cases, agency policies have been very clear and specific, but the ward/unit has developed its own procedures not in conformance with the policies. Over time the procedures have become the norm and some staff are not even aware of the “official” policy. This happens frequently in reference to bathing policies and procedures. For example, these policies may require that individuals with certain disabilities be observed constantly or may require staff members to keep their own hand under the water when using hand-held shower hoses so that the staff can react immediately to any change in water temperature. But, common practice is to check the water temperature when initially starting the shower and then use one’s hand to assist the individual in any way he/she requires.

It is particularly sad in cases when something has gone wrong – a scalding due to a sudden temperature change, for example – to watch administrators, who have turned a blind eye to the common practices, dust off the policies and righteously charge staff with violations.

Lessons Learned

The intent of a self-examination of agency policies is to insure that each is truly a tool of quality assurance and not a risk management artifice. Some of the questions facilities should ask in this process include:

- Are the policies clear and do they cover reasonably foreseeable circumstances?
- Have we promulgated the policies widely to all levels of relevant staff? Have we given staff time to study a policy and ask questions?
- Have we devised a method whereby administrators can be sure that staff understand a policy and how to implement it?
- Have we created a work ethic and a forum where staff can report those instances where they were not implementing a policy as intended? Are staff encouraged to identify what they would need to fully implement the policy, e.g., equipment, increased staffing, access to consultants, more time, reprieve from other obligations, etc.?
- Have we, as an agency, made a commitment to carefully consider the input from staff and make whatever program and/or policy modifications are possible to meet the needs of staff directly implementing the policy, consistent with the objective of the policy?

Agency Self Assessment

1. Could this happen in our program? Yes No

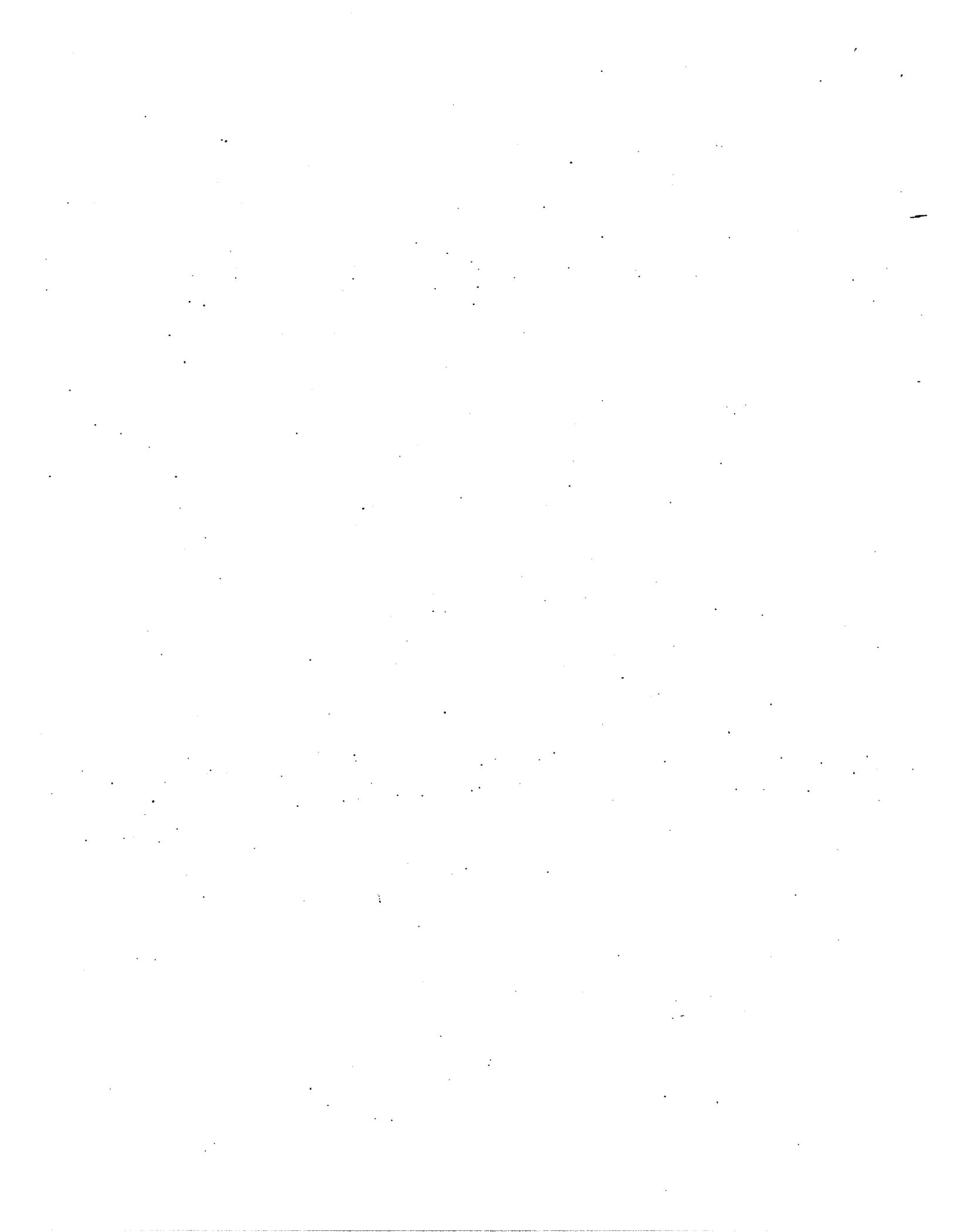
2. What lessons, if any, are applicable to our program?

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 Becky Newman:

A Failure to Communicate in Sexually Related Incidents

Case #16

The Incident

One spring evening, Becky Newman¹ was observed in a men's room toilet stall with Tony Iorio. Both were participants in a Friday evening social/recreational program sponsored by an agency serving developmentally disabled adults. They were discovered by a third program participant who reported his observation to staff on duty that evening.

By the time staff were informed and responded, Ms. Newman and Mr. Iorio were no longer in the bathroom. Ms. Newman was located in her choral group; Mr. Iorio was found in his cooking class.

In the privacy of an office, Ms. Newman was interviewed about what had transpired earlier that evening. Haltingly, she disclosed that while on break between activities, she had followed Mr. Iorio to the men's room. Once inside, she reported, Mr. Iorio began kissing her, took off his pants and then pulled hers off. He then put his "thing," as she phrased it, into her; she pointed to her vaginal area. She claimed she knew she had to get out of the bathroom, screamed, pulled on her clothes and left the bathroom to rejoin her group. During the interview, Ms. Newman seemed visibly upset.

The Individuals

Becky Newman was a 33-year-old woman diagnosed as functioning in the moderate range of mental retardation. Verbal and ambulatory, Ms. Newman required assistance in most activities of daily living. She was also very sociable, but had difficulty with establishing boundaries in her relationships with male peers: she tended to acquiesce to any of their suggestions. She was assessed not to have the capacity to consent to sexual activity and had received training on sexuality issues.

Ms. Newman lived in a community residence with other developmentally disabled adults, worked in a sheltered workshop and attended the Friday recreation program offered in her neighborhood which was where she had met Mr. Iorio many months earlier.

Mr. Iorio lived in a community residence sponsored by a different agency. Twenty years old, he too functioned in the moderate range of mental retardation. Verbal, ambulatory, and proficient in most activities of daily living, Mr. Iorio was apparently believed by staff of his residence to have the capacity to consent to sexual activity. He was known to be sexually active in his residence and had received sexuality training.

Mr. Iorio viewed Ms. Newman as his girlfriend. He also knew that a fellow resident of his group home, Tommy, liked Ms. Newman and believed she was *his* girlfriend. Staff of the recreation program, which all three clients attended, were aware of this "triangle" involving the two male residents of one residence and Ms. Newman, who lived in a different home.

The Investigations

Upon Ms. Newman's disclosure of nonconsensual sexual activity, the recreation program immediately notified police, arranged for Ms. Newman's physical examination at a local hospital, and commenced an internal investigation.

During police interviews, Ms. Newman, in her own terminology, indicated that she and Mr. Iorio had intercourse in the bathroom and that she felt it was wrong...she didn't want to do it. She reported that she screamed, but no potential witnesses could corroborate that.

Mr. Iorio told investigators that Ms. Newman followed him into the bathroom, they kissed, and that he pulled off his pants and hers. Using his own terminology, he indicated that they next had intercourse. Mr. Iorio saw nothing wrong in his actions as Ms. Newman was his "girlfriend."

¹ All names are pseudonyms.

Ms. Newman arrived at the hospital within about two hours of her disclosure. Her parents and staff of her residence also went to the hospital. There, a physical examination revealed she was having her period. No evidence of penetration or physical trauma to the vaginal area was found. Tests for sexually transmitted diseases were conducted, and Ms. Newman received antibiotic therapy as a precautionary measure to combat any infection possibly transmitted through the reported sexual contact.

Police officers conferred with staff of the District Attorney's Office, and it was decided, in light of the available evidence and the clinical histories of the individuals involved, that the matter would not be pursued criminally but should be handled administratively and clinically, by the involved care providers.

Additional Investigations/Reviews

In the ensuing administrative and clinical reviews, it was determined that Mr. Iorio and Ms. Newman had engaged in some form of intimate sexual activity. Although there was no evidence of force, it was clear that Ms. Newman lacked the capacity to provide consent to the activity that had transpired. As such, it was determined that she had been sexually abused.² To better protect Ms. Newman, who had been victimized, and Mr. Iorio, who saw nothing wrong with his actions, it was recommended that their primary providers, the community residence agencies, provide both with additional training and counseling on issues pertaining to sexuality.

It was also found that the opportunity for the sexual encounter was created by a staffing problem. During the 15-minute break between the formal recreational activity sessions, a staff member—assigned to monitor a hallway where bathrooms were located—left his post to bring needed supplies to one of the activity rooms. During this interval, apparently, the two clients gained access to the bathroom unnoticed by staff. The recreation program subsequently realigned staff coverage during break times to ensure adequate supervision.

A Forewarning Not Well Communicated/Appreciated

Most importantly, the investigations revealed that Ms. Newman had been sexually abused at the recreation program one week prior to this incident and that this was not communicated clearly or appropriately by her residential program to the recreation program or other parties.

One week before Ms. Newman was discovered in the bathroom stall with Mr. Iorio, she reported to residence staff that while at the recreation program, Mr. Iorio, along with Tommy, had fondled her breasts and touched her vagina.

The residence manager immediately called the recreation program to report her allegation. What was verbally reported, however, is unclear. The residence manager claimed he reported the particulars of Ms. Newman's complaint: the unwanted fondling. The residence manager, however, did not file any written report of abuse as required by state regulations. The recreation program manager indicated that he was only told that Ms. Newman was "uncomfortable" with Mr. Iorio and Tommy, which is what he recorded in a contemporaneous note of his telephone conversation with the residence manager. The recreation manager claimed that he was not told about Ms. Newman's allegations of unwanted fondling. However, he also admitted that he did not probe what the residence manager meant when he said Ms. Newman was "uncomfortable" with Mr. Iorio and Tommy; the recreation manager assumed Ms. Newman was "uncomfortable" with two men from a different residence claiming they were her boyfriends.

Neither Ms. Newman's residence nor the recreation program notified Mr. Iorio's or Tommy's residence of her specific allegation of abuse or her more generalized sense of discomfort. And over the next week no further action was taken until Ms. Newman returned to the recreation program and was victimized by Mr. Iorio in the bathroom.

² Sexual contact between staff (including contractors or volunteers) of agencies and consumers is defined as sexual abuse in state regulations, as is sexual contact between consumers, unless the consumer(s) is a consenting adult.

Lessons Learned

To quote dialogue from *Cool Hand Luke*, "What we have here, is a failure to communicate." And consequently, Ms. Newman was sexually exploited and abused.

Warnings of the potential for abuse were not effectively communicated to relevant care providers. Although Ms. Newman's residential program was aware of her specific complaints of inappropriate sexual fondling, her recreation program was left to believe she felt "uncomfortable" about having two boyfriends; the residential program serving the individuals who initially fondled Ms. Newman was kept totally out of the loop of communication over Ms. Newman's concerns and allegations. One week later, absent any additional protections, Ms. Newman was abused more seriously.

Ms. Newman's unfortunate sexual molestation illustrates and underscores the vital need for clear and accurate communication among service providers caring for disabled persons: As the service system continues to move from an institutional model, where all services are offered under one roof by one agency, to a variety of community-based models, the number of care providers and agencies directly or indirectly involved in individuals' lives grows, creating increased communication challenges and risks for miscommunication.

To ensure the well being of the individuals they serve in concert with other providers, agencies must periodically review the adequacy of communication with fellow care providers. This is a process in which all levels of staff should be involved, questioning:

- When significant events occur in an individual's life—be they changes in medications, treatment plans or health status, or allegations of abuse or general complaints about care—are they communicated to all appropriate service entities which should play a role in evaluating, monitoring, or remedying problems arising from the event?
- In notifying other parties of such events, is care taken to provide sufficiently specific information to enable the other parties to evaluate, monitor, or remedy the situation? Is care taken to avoid vague and ambiguous terminology, such as, "She feels uncomfortable," and to provide objective behavioral data, such as, "She alleges Mr. Iorio and Tommy fondled her breasts"?
- Are verbal reports to other care providers followed up with written reports to ensure no miscommunication?
- Where ambiguous reports on important events in a client's life are received, such as, "She feels uncomfortable," do agency staff probe for more details to better assist them in their protective and service role?
- And, based on the nature of the event disclosed and shared, do the agencies collectively formulate and agree upon a plan of corrective/protective action?

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 Joel Lang:

A Failure to Ensure Implementation of a Discharge Plan

Case #17

Introduction

Mr. Joel Lang¹ is a 38-year-old man who had lived on his own, had a girlfriend and drove a taxi cab. He is a quiet man who had lived a simple life. He did, however, have a history of periodic episodes of depression. One recent spring, he was admitted to a university hospital for treatment of an asthmatic condition. Once he was medically stable, Mr. Lang complained of depression. He was screened through the psychiatric unit of the hospital, determined to need inpatient treatment, and sent to a state psychiatric center for treatment of depression. Mr. Lang had had previous short-term hospital stays for depression, but had not needed inpatient treatment for the last three years. Mr. Lang also had numerous health problems including chronic obstructive pulmonary disease, asthma, bronchitis, congenital pulmonary artery disease and obesity, and these had required his hospitalization more frequently.

Course of Treatment

Upon his admission to the state psychiatric center, Mr. Lang was diagnosed as depressed. Because he had expressed a desire to hurt himself, he was placed on a 1:1 level of supervision as a suicide precaution. During his two-and-a-half-week hospitalization, Mr. Lang was very cooperative and friendly to both staff and other patients. With psychotropic medication, he was soon able to express his feelings and needs to staff and reported that he no longer had suicidal thoughts. The 1:1 level of supervision was removed, and during the rest of his hospital stay, Mr. Lang participated in therapeutic groups and socialized and laughed with fellow patients. Medications for Mr. Lang's multiple medical needs included Prednisone 5 mg three times daily, Theo-Dur 300 mg twice daily and the use of a Ventolin inhaler for treatment of his respiratory problems.

Mr. Lang received a physical exam on the day he was admitted to the state psychiatric center. The examining physician ordered routine blood work, but the blood was not drawn by nursing staff until three days later. There is no reason documented in the record to explain the delay. The blood was sent to the lab for evaluation, and four days later the results were documented in Mr. Lang's record indicating he had a very high blood glucose level of 347 (normal range 70-110). Additional tests were ordered which confirmed the high blood sugar. Specifically, the postprandial (following a meal) level was 667 and a repeat finger stick test showed a level of 419. Mr. Lang had no history of diabetes or any related condition.

The treating physician ordered further evaluation to rule out diabetes mellitus and considered the possibility that the symptoms might be a side effect of a medication. He described Mr. Lang as asymptomatic, and ordered that Prednisone (medication for Mr. Lang's asthmatic condition) be tapered.

At the same time that Mr. Lang was undergoing the evaluation of possible diabetes, the treating team determined that he was ready for discharge, as he was no longer depressed or suicidal. In fact, the day after the second set of blood glucose levels was posted, Mr. Lang was discharged.

The Discharge Plan

Mr. Lang's treating psychiatrist believed that his patient needed inpatient evaluation of what was likely diabetes. He arranged with Mr. Lang's personal physician that he (the personal physician) would admit Mr. Lang into a community hospital immediately following his discharge from the state psychiatric center. The discharge plan developed for Mr. Lang specified that he required admission to the hospital for the treatment of his diabetic condition. Consequently, he was discharged without medication or any alternate living arrangement.

¹ A pseudonym.

A social worker from the psychiatric center accompanied Mr. Lang to the hospital. She spoke with the receiving nurse, filled out the necessary paperwork and waited approximately one hour for Mr. Lang's private physician to come to the emergency waiting room to admit him. After an hour, the social worker left Mr. Lang alone waiting for admission.

It is not clear what happened at this point, in part because Mr. Lang cannot recall how much longer he waited. Because he was not medically evaluated in the emergency room, the hospital has no record which would clarify what happened and when. In any case, Mr. Lang says he heard the nurse call his name, and he got frightened and left the waiting room without identifying himself.

There was no follow-up by the general hospital, Mr. Lang's personal physician, or the psychiatric center to determine what had become of Mr. Lang.

Subsequent Events

Ten days after he left the emergency room frightened, Mr. Lang went to another general hospital complaining of severe leg pain. He was admitted. During the ten days between hospital visits, Mr. Lang was not in touch with any service provider, but reportedly stayed with his girlfriend. During that time he also missed a scheduled appointment at an outpatient clinic. Two days after his admission for leg pain, the surgeon performed a bypass operation and attempted to remove a clot which had formed in Mr. Lang's leg. These procedures were unsuccessful, and within a week Mr. Lang required a below-the-knee amputation of his left leg. Mr. Lang recuperated in the hospital for several months and was then transferred to a nursing home for the fitting of a prosthesis and further physical therapy.

Lessons Learned

Mr. Lang's story is sad, not only because of the serious, life-altering consequences of his decision to leave the emergency room before he was admitted, but also because no one took the time – not his escort from the psychiatric center or his physician – to check on how he was doing. What the human heart fails to attend to, law sometimes tries to prescribe. This is the case with discharge law in New York State (Mental Hygiene Law Section 29.15). It places on the facility the obligation to establish a discharge plan which meets an individual's needs and ensure that it has been implemented. The discharge plan established for Mr. Lang appeared appropriate, i.e., it addressed his immediate need for hospitalization; the implementation was flawed and went undetected until a tragedy occurred.

Surely there are lessons to be learned here about the importance of ensuring that the basic provisions of a discharge plan have been implemented – the former patient's living arrangement is satisfactory, and he/she has made the connection with the outpatient provider and with other providers of services essential to this individual's well-being. But, there are also other lessons in these events which are less glaring:

- Delays in securing blood work and lab results while Mr. Lang was in the psychiatric hospital postponed the verification of his high blood glucose level until the day before he was released. This left very little time for nursing staff to teach Mr. Lang about his diabetes. Not surprisingly, when he was interviewed in the nursing home where he was recuperating, Mr. Lang, depressed over the loss of his leg and the long rehabilitation ahead of him, stated that he did not know that the consequences of the illness could be so grave. The psychiatric center has since taken measures to ensure the timely implementation of physicians' orders for tests and the quick filing of lab results for the physician's review.
- While it was commendable that the facility attempted to secure the services of Mr. Lang's personal physician at his request, either the communication between the two physicians was flawed or the personal physician did not fulfill his obligation to meet his patient in the emergency room in a timely manner or communicate with the emergency room that he was running late and ask that the patient be assured he was indeed coming.

- The psychiatric center staff member made an error in judgment when she left Mr. Lang alone in the emergency room after an hour and the physician had still not come to admit him. Psychiatric center staff, when questioned, later said that they believed that because Mr. Lang was no longer depressed and was ready for discharge, he could manage the process of "admission through the ER" on his own. This does not seem to take into account that Mr. Lang had no friends or family with him, was entering the hospital for treatment of a new disease with which he was unfamiliar, and his serious depression had only recently lifted. It also does not consider the possible effects of Mr. Lang's high blood sugar on his judgment and physical stamina. What would have been an ordeal for anyone, became overwhelming for Mr. Lang.

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 Donna Osborne:

Providing Life-Saving Treatment Over Objection

Case #18

Background

Donna Osborne¹ was born and raised in rural upstate New York. Her death at age 37 marked the end of a troubled life. While little is known about her childhood years, a clearer picture emerges with her early adulthood.

While in her early 20s, Ms. Osborne married a man from a Middle Eastern country. They soon had a daughter. However, when her daughter was about eight years old, Ms. Osborne's husband reportedly "kidnapped" the child and returned with her to his native country; Ms. Osborne never saw her daughter again.

It is not clear whether Ms. Osborne's abuse of substances started with this incident, or was a pattern of behavior prior to the reported abduction, but in the years which followed, Ms. Osborne regularly abused multiple substances including benzodiazapines, marijuana, cocaine (intravenously), and alcohol.

In her last ten years, Ms. Osborne was admitted to psychiatric facilities on a number of occasions for treatment of depressive symptoms, manifested in suicidal ideation, and for detoxification. However, soon after release from these settings, Ms. Osborne would become noncompliant with recommended psychiatric treatment and would resume substance abuse. She lived in a variety of settings (e.g., with friends or relatives) and sometimes "on the streets." She reported that periodically she was beaten, robbed and, on one occasion, raped.

Ms. Osborne's psychiatric diagnoses included mixed personality disorder, acute adjustment disorder, and chronic mixed substance abuse. Ms. Osborne also suffered from a number of medical maladies including asthma, seizure disorder, nonactive pituitary adenoma and breast cancer, which necessitated a mastectomy approximately one year before her death.

Ms. Osborne's last admission to a psychiatric unit of a general hospital occurred in the summer of her 37th year. She was brought to the hospital by police after she threatened to kill herself with a friend's gun.

Upon admission, Ms. Osborne claimed she was depressed; she appeared tired and also angry over having been admitted to the hospital involuntarily. She admitted to suicidal ideation and very recent (within 24 hours) cocaine use, but denied hallucinations and delusions.

Soon after admission, Ms. Osborne denied further suicidal ideation; she claimed her earlier threat of self-harm was just an impulse. And during the course of her one-week hospitalization, there was no evidence of psychosis. However, she requested ECT to, as she put it, "help me forget" past incidents, including a recent rape and beating. Ms. Osborne's chronic substance abuse was noted and explored; it was felt that it was the underlying cause of her persistent dysphoria and occasional erratic and impulsive behavior. ECT was deemed not indicated, but Ms. Osborne was resistant to suggestions concerning drug treatment, as she had been in the past.

She requested discharge and was released with referrals to an outpatient psychiatrist and an internist for follow-up of a urinary tract infection (UTI) which had been diagnosed. Her discharge medications included Proventil and Theo-Dur for asthma and Klonopin for her seizure disorder, which she had been taking prior to admission, as well as Keflex for her newly diagnosed UTI.

The Incident

Within a week of discharge, Ms. Osborne went to her internist's office and confided that she had relapsed into alcohol and cocaine abuse and felt depressed. The internist contacted the psychiatrist who suggested voluntary admission to the local hospital the next day.

¹ A pseudonym.

However, Ms. Osborne told the internist that if she went home that night, she'd kill herself. She was immediately sent to the local general hospital where she was examined in the emergency room.

During her evaluation in the ER, Ms. Osborne was alert and oriented. However, she admitted to suicidal ideation and stated she planned on killing herself by jumping from a bridge. Upon examination by a psychiatrist, it was decided to admit Ms. Osborne involuntarily to the hospital, as an emergency admission, pursuant to Section 9.39 of Mental Hygiene Law.

This section of Law permits the involuntary hospitalization of individuals who are mentally ill for immediate observation, care and treatment, as their mental illness is likely to result in serious harm to self or others. The likelihood of harm may be manifested by suicidal, homicidal or violent behavior, as well as other behavior likely to result in serious harm if there is not immediate hospitalization, such as the mentally ill person's inability or refusal to meet essential needs, including health care needs.

The examining psychiatrist completed the necessary paperwork certifying his examination of the patient and his belief that Ms. Osborne was suffering from a mental illness for which immediate care and treatment was required, lest it result in the likelihood of serious harm to self or others.

As Ms. Osborne was awaiting transport to the hospital's psychiatric wing, she confided to an ER security officer that she had taken all of her asthma medication. She stated she ingested the pills in the ER while waiting to be examined by the psychiatrist. (By this point, Ms. Osborne's personal effects, including her purse and any medication vials, had already been sent home with a friend who had accompanied her to the ER and left when it was decided Ms. Osborne was going to be admitted.)

The security officer alerted other ER personnel, and toxicology tests were conducted. They indicated Ms. Osborne had a lethal Theophylline level of 58 (normal range: 10-20; toxic range; 30-40; Lethal Range: 50-250).

Ms. Osborne was immediately transferred to a medical service for treatment of a possible suicide attempt by drug overdose. There, the initial orders called for placement of nasogastric tube, gastric lavage and charcoal treatment, as well as Ipecac. However, Ms. Osborne refused these treatments, which are standard protocols for drug overdoses.

Ms. Osborne did allow placement of an IV line for hydration, but over the next 24 hours, she refused standard treatments for a drug overdose. Her refusals were honored. During this period, Ms. Osborne became more sluggish, developed vomiting, and had difficulty speaking. A repeat toxicology study indicated that her asthma medication level had dropped to 40; however, after her death, it was discovered this was a laboratory error — her true level was over 120.

By the 24th hour of her hospital admission, Ms. Osborne had lapsed into a coma and began developing seizure activity and rapid heartbeat. Anticonvulsants were administered with little effect, and on the next morning, Ms. Osborne expired. The cause of death was attributed to antiasthmatic drug overdose.

What's Wrong With This Picture?

- A woman states she is going to kill herself.
- She is brought to a hospital, found to be mentally ill and suicidal, and a decision is made to admit her to the hospital involuntarily, for observation, care and treatment because her illness constitutes a danger to herself.
- While in the emergency room of the hospital, the woman takes a drug overdose and announces it to staff.
- She is immediately transferred to a medical service for treatment of the confirmed overdose. But, the patient refuses the recommended standard treatments for a drug overdose; her refusals are honored and she dies.
- The facility conducts an internal review and, aside from the false low Theophylline level — the result of a laboratory error, finds no problems in the patient's care.

Answer: Everything!

Ms. Osborne was admitted to the hospital involuntarily because she was suicidal. Yet when she overdosed on medications while in the hospital, necessary medical treatment was withheld pursuant to her wishes and she was allowed to die, a suicide.

New Policies

Following the Commission's investigation into Ms. Osborne's death, the hospital formalized policies, which had not existed previously, concerning the treatment of mentally ill adults over their objections. The facility also provided training in the new policies for staff of its psychiatric and medical services.

The policies clarified that in psychiatric emergencies (i.e., where a patient's conduct is dangerous, meaning it constitutes a risk of physical harm to self or others) treatment can be rendered to ameliorate the danger regardless of the patient's admission status or objection.

For medical emergencies, the policies clarified that treatment can be rendered over objection if the patient lacks the capacity to consent in the opinion of a qualified consultant and the director of the mental health unit.

For situations which are not emergencies yet psychiatric or medical care is indicated, the policies call for a determination of the patient's capacity to consent (or withhold consent) to the recommended treatment. If it is determined that the patient lacks the mental capacity to consent and treatment is indicated, the facility will secure a court order for treatment.

Lessons Learned

Ms. Osborne's suicide may well have been averted if the hospital to which she was involuntarily committed had policies in place to guide staff actions in cases of mentally ill patients objecting to treatment.

Today, the concepts of individual choice and personal responsibility have taken on increased importance in the field of caring for people with mental disabilities. And this is good; it counterbalances society's at times overly paternalistic attitude towards individuals with disabilities and remedies some of the sins associated with that philosophy: unnecessary institutionalization, deprivation of liberties, coerced treatment.

However, as the case of Donna Osborne illustrates, there continues to be a need to ensure that all staff are aware of the limits to patients' choices and the starting points of their professional responsibilities to ensure patients do not harm themselves or others. Facility administrators and their staff should consider:

- Does the agency have policies which guide staff actions when a mentally disabled individual objects to recommended treatment?
- Do the policies differentiate between emergency situations and nonemergency situations?
- Do the policies, in emergency situations, promote the prompt delivery of necessary care and treatment?
- In nonemergency situations, do the policies promote timely evaluations of a patient's capacity to consent or object to treatment and, if the patient lacks capacity, for securing consent in a timely fashion from an authorized surrogate?
- Do the policies promote the continuing education of patients who object to treatment concerning the nature of treatment and the risks and benefits associated with receiving the treatment and objecting to treatment?
- Do all staff, not just staff of the psychiatric service/unit, have a working knowledge of the policies?

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 Alanis Petty:

When Investigations Miss the Basic Facts

Case #19

Alanis Petty¹ was 35 years old and 7½ months pregnant when she walked from the passenger waiting area of a Long Island railroad station and lay down in the path of an oncoming train. She died instantly, and the fetus could not be saved. Based on eyewitness accounts, the death was clearly a suicide.

Just several hours earlier, Ms. Petty had eloped from the psychiatric unit of a local hospital. Police officers, aware of the elopement and responding to a report of a suicide, identified the body at the train station as Ms. Petty's. The police notified the hospital, which in turn reported the death to appropriate external parties and commenced an investigation into the incident.

The facility's investigation revealed no deficiencies in the care provided Ms. Petty:

- She had been admitted to the hospital one week prior with depressive symptoms and suicidal ideation.
- Within days her mood improved, and she denied thoughts of suicide.
- On the day of death, she left her unit for an outing with a group of patients and staff; however, she got on an elevator ahead of the group, the elevator doors closed quickly, and she absconded.
- Police were promptly notified of the elopement.

But one question nagged Ms. Petty's family, and Commission staff who reviewed the facility's investigation report: How could a 7½-month pregnant woman get ahead of her group and away from staff so quickly, and so promptly vanish?

Alanis Petty

Ms. Petty's first known psychiatric hospitalization occurred when she was in her mid-20s. According to records of that hospitalization, she had a several-year history of psychiatric difficulties and sporadic outpatient treatment. Her hospitalization was precipitated by poor sleep patterns, anxiety, hyperactivity, pressured thoughts and a total inability to function.

During her nearly three-week hospitalization, Ms. Petty was diagnosed as having bipolar disorder, manic type. She was started on lithium, which had good results. She was discharged to her home, where she lived with her husband, with plans for outpatient care and medication therapy and monitoring.

In the years following, Ms. Petty worked part time, and she and her husband had a son. Her psychiatric difficulties continued, and she was reportedly seen by a number of private physicians who at various times prescribed lithium, Prozac, Elavil, and Ativan. According to family members, Ms. Petty's manic phases usually occurred in summer months and were manifested in provocative dress and hypersexuality.

During one such episode in the summer before her death, Ms. Petty left her husband and seven-year-old son to live with an old boyfriend. By the fall of that year, Ms. Petty was pregnant; she was also the target of her boyfriend's physical abuse. Ms. Petty left his domicile and returned to her husband and son.

Although reconciled with her family, Ms. Petty faced a number of stressors: deeply religious, Ms. Petty was reportedly ostracized by her church community over her infidelity; she faced legal proceedings involving her boyfriend over paternity and abuse issues; and, although reunited with her husband, she carried another man's child and was ambivalent about having the baby.

¹ A pseudonym.

By the spring, the stressors took their toll. Ms. Petty had difficulty sleeping, felt depressed, overwhelmed, anxious, and suicidal. She went to the hospital seeking psychiatric help.

Ms. Petty's Last Hospitalization

Upon presentation at the hospital's emergency room, Ms. Petty recounted her past and more recent history, the stressors in her life, her depression, self-denigrating ruminations, and her thoughts of suicide.

Ms. Petty was assigned the diagnoses of R/O depression and R/O bipolar disorder. For the first several days, she was placed on a heightened level of supervision. This was discontinued as Ms. Petty denied suicidal ideation. She did, however, voice concern about being a burden on her family or spending the rest of her life in an institution. At various points, she seemed sad.

According to the records and Commission interviews with staff, considerable attention was given to providing Ms. Petty psychotropic medications, and this issue was discussed between her psychiatrist and OB/GYN physician. Lithium, which had worked well in the past, was considered, but ruled out due to the potential danger to the fetus. Other, less potentially harmful, psychoactive agents were deemed desirable, but Ms. Petty refused them as she was concerned about their impact on her pregnancy.

Ms. Petty reportedly wished that birth could be induced early so that she could begin taking psychotropic medications, but this was contraindicated by her physicians.

During her one-week hospitalization, Ms. Petty enjoyed several outings off her locked unit, accompanied by staff and, on the day before her death, her husband. The outings occurred without incident and, according to her husband when she was last with him, Ms. Petty gave no indication or suggestion of what would transpire the next day. While Ms. Petty was allowed off her unit accompanied by family or staff, her psychiatrist did not believe she should be allowed unescorted leaves.

The Incident

On the day she died, Ms. Petty woke and participated in the unit's activities. According to staff she was talkative, socialized with peers, and seemed happy. One of the activities that morning was planning and preparing the midday meal. Patients would plan the meal and volunteer to serve in groups which would shop for the foodstuffs, do the actual cooking, and clean up when the meal was over. Ms. Petty volunteered to go on the shopping expedition and to help in the cleanup after the meal.

Ms. Petty and one other patient were chosen to accompany three staff, two women and one man, to the local supermarket to purchase the meal's ingredients. Careful examination of what next transpired revealed that Ms. Petty did not get ahead or run away from the group, as was implied by the facility's investigation; rather, she was left alone while off the locked ward.

In planning the shopping trip, the three staff agreed that the male staff member would take Ms. Petty and the other patient from the second-floor locked ward and wait by the elevator area on that floor while one female staff person went to another unit to pick up a cellular phone taken on all outings and the other female completed some paperwork. They'd all meet by the elevator.

The male staff member and Ms. Petty and the other patient left the locked unit and went to the elevator area and waited, and waited. When neither of the other two staff showed up, the male staff member told Ms. Petty and the other patient to wait while he went to look for the other staff.

The male staff person left the two patients by the elevator and proceeded to the unit where the cellular phone was kept. He rang the bell; no one answered. Using his keys, he opened the door and entered the unit to look for his colleague who had been dispatched to retrieve the cellular phone. He estimated that he left the two patients alone at the elevator for only minutes. He found his colleague. Together, the two staff returned to the elevator area but found only one patient — Ms. Petty was gone. The remaining patient reported that while they were left alone, an elevator came, Ms. Petty boarded it, and left.

The two staff and the patient walked to the first floor to look for Ms. Petty, but did not find her. They returned to the unit and reported what occurred, which triggered a building search with no results, and notification to police. Several hours later, and 15 miles away, Ms. Petty was struck by the train.

Discussion

The events of the day of Ms. Petty's death — her being left alone by staff in an elevator area, her getting on the elevator and leaving the facility while unsupervised, etc. — were well documented in staff statements given to the facility immediately after the incident. They, however, were not considered by the facility in its review, until the Commission reaffirmed the statements in subsequent interviews and confronted facility administrators with the evidence. While the facility in its internal review focused on the complexities of Ms. Petty's clinical (i.e., psychiatric, medication, and OB-GYN) care and concluded that all was appropriate — a conclusion supported by the Commission, it failed to examine more practical matters: the mechanics of her escape, the adequacy of her supervision, and the implications concerning supervision of patients in the future. Without addressing these issues, it concluded simply that Ms. Petty eloped when she got ahead of her group, but received adequate care.

Upon receipt of the Commission's findings, the facility re-examined the events surrounding Ms. Petty's elopement and death. It agreed that material aspects concerning Ms. Petty's elopement and death were not carefully examined, and indicated that in the future, its Quality Assurance Committee would explore all aspects of untoward events.

Additionally, while acknowledging that staff erred in judgment by leaving Ms. Petty alone while on an off-ward activity, the facility indicated it had no policies to guide staff conduct in such matters. As such, it revised its policies to ensure that physicians approving patient participation in off-ward activities also indicate the level of supervision the patient requires while off ward. Additionally, the facility revised its policies to ensure that all equipment and staff required for an outing be assembled on the unit before patients leave on the outing.

Lessons Learned

All untoward events offer potential opportunities for learning and preventing the occurrence of similar incidents, if one is willing to look and keep an open eye. In Ms. Petty's case, the facility appropriately looked at critical clinical issues — her suicide potential, her medication management, her recent behavior and mental status, etc. — and concluded her death was unpredictable and suggested no quality of care issues. Blinded by these heady issues, however, the facility failed to examine more practical ones, chiefly how did Ms. Petty leave the facility; why was she left alone; and what does this mean about supervision of patients on future outings? The facility's eyes were opened to these realities only after an external party intervened. If such had not occurred, staff would not have received the policy guidance they needed on future outings, and patients would have been left vulnerable.

All facility administrators and staff should ask themselves to what extent their quality assurance mechanisms are eye-opening vehicles, or canes to assist in navigating a half-seen world.

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 Juan García:

Errors Spanning Three Shifts Lead to Death

Case #20

Background

Juan García¹ was born in Puerto Rico in 1962. Very little is known about his early childhood, except that he was involved in an accident resulting in paralysis to the left side of his body and a seizure disorder. His family relocated to New York State.

At five years of age, Juan was admitted to a children's psychiatric center in New York and was subsequently transferred to an out-of-state program where he lived until the late 1980s. There he was diagnosed as having moderate mental retardation, as well as a seizure disorder and emotional difficulties manifested in poor impulse control, disruptive behavior, and verbal — but rarely physical — confrontations with his peers. He was maintained on a regimen of anticonvulsant and antipsychotic medications.

In the late 1980s, Mr. García returned to New York State to reside in a program serving 40 developmentally disabled individuals. Verbal and ambulatory, Mr. García was able to communicate his needs and complete most activities of daily living, if provided verbal or physical prompts by staff. Slightly overweight, he was placed on a diet, but would occasionally steal food from others. Over the next five years, Mr. García lived without major incident in his group home; he was maintained on a medication regimen to control his seizure and emotional disorders, but generally enjoyed good health, consistent with a man in his early thirties.

The Incident

On a cold winter Saturday night, two staff of Mr. García's residence "called in sick." This left only three staff, two of whom were working overtime, to care for the facility's 40 residents during the overnight shift. Minimal staffing patterns called for five staff to be on duty.

According to the three staff who worked that shift, the night progressed without incident. However, at about 6:00 a.m. on Sunday morning, as staff were waking and assisting residents in their morning activities, the shift supervisor discovered Mr. García in the downstairs common area with what appeared to be white powder around his mouth and on the front of his shirt.

The shift supervisor attempted unsuccessfully to determine what, if anything, Mr. García had eaten.

Approximately two hours later, the residence cook arrived for duty. The shift supervisor told her about finding Mr. García with white powder on his face and shirt. With the cook's assistance, it was determined that Mr. García had ingested a bowl of baking soda, kept in the facility's microwave oven to cut down on odors. The cook's and shift supervisor's investigation further revealed Mr. García had also gotten into the freezer and had eaten some frozen hot dogs and raw bacon. The shift supervisor called an on-call administrator and reported these findings to her. The administrator advised the shift supervisor to monitor Mr. García.

At approximately 10:00 a.m., the day-shift supervisor arrived for duty. As she relieved the night-shift supervisor, she was briefed on the events of the previous shift and Mr. García's "baking soda" incident and the instructions to keep an eye on Mr. García.

Starting at about 11:00 a.m. Sunday morning, Mr. García began experiencing severe and recurrent episodes of vomiting and diarrhea. The day-shift supervisor alerted the on-call administrator of this after noon. The administrator instructed her to call the agency's on-call nurse, which the supervisor did.

Informed that Mr. García had ingested baking soda and other materials earlier that day and was now experiencing severe bouts of diarrhea and vomiting, the nurse told the residence supervisor to call EMS to transport Mr. García to the local hospital. This was done, and Mr. García arrived at the hospital at approximately 2:00 p.m. Sunday afternoon.

¹ A pseudonym.

Upon arrival, Mr. García presented as nonverbal and sluggishly responsive to painful stimuli; he then became agitated and confused, and required restraint. The findings of a physical examination were essentially within normal limits, but laboratory results were abnormal, indicating an electrolyte imbalance. Mr. García was assigned the diagnosis of hypernatremia (i.e., excessive sodium in the blood) and dehydration secondary to vomiting and diarrhea from the ingestion of baking soda.

Over the next 24 hours, Mr. García was hydrated in an attempt to replenish the volume depletion, caused by the diarrhea and vomiting, and to stabilize his body chemistry.

The attempts were unsuccessful. Mr. García developed seizure activity and, despite attempts to control his seizures with medications, he expired. His death, according to hospital records, was attributed to "extreme depletion of bodily fluids due to poisoning by alkalizing agent — baking soda."

Investigation Results

The investigation into the events culminating in Mr. García's demise indicated that he was the victim of neglect and suffered a preventable death. The lapses in performance and judgment spanned three shifts and were compounded by on-call administrative staff:

- Although existing agency policies called for a shift supervisor to ensure sufficient staff for the next shift, such was not done in this case. The evening-shift supervisor, who had a total staff complement of ten people, did not hold over or call in relief staff to cover for the overnight shift, which requires five staff, two of whom had called in earlier indicating that they could not report for work.
- At the change of shift, the overnight supervisor — faced with a shortage of two staff — did not notify on-call administrative staff to request their assistance; he believed he could manage the residence of 40 clients with only three staff, including himself.
- Although the night passed without incident, at 6:00 a.m. — a peak hour for staff and resident activity (between residents waking up, staff assisting them with morning hygiene routines, etc.) — it was discovered that Mr. García, unsupervised, may have ingested an unknown substance. Yet, the night supervisor did not inform on-call administrative staff of the situation.
- Two hours later, when the cook arrived for duty and it was determined Mr. García ingested a large quantity of baking soda and some raw meat, the on-call administrator was contacted. Rather than advising the residence to contact the agency nurse or Poison Control for advice, the on-call administrator — who was not a medical professional — advised staff to keep an eye on Mr. García.
- This advice was passed on to the oncoming day-shift supervisor. Not told of what to look for, and unaware of the significance of Mr. García's symptoms, the day-shift supervisor did not contact the on-call administrator to alert her to Mr. García's profuse vomiting and diarrhea for more than an hour. It was only at this point, at least six hours after Mr. García had ingested the substance which caused his death, that the residence was instructed to secure medical attention.

Lessons Learned

Although Mr. García was transported to a hospital in a timely fashion once the order to get medical attention was issued, he could not be saved. The cumulative effect of the series of mistakes starting more than 12 hours before his hospital admission could not be undone. As a result of the investigation, the agency instituted corrective actions, including policy revisions and training and disciplinary activities.

However, the events leading to Mr. García's death offer several lessons for other agencies serving individuals with disabilities:

- Are minimal staffing standards stringently enforced, and are all staff aware of the critical importance of these standards? They are more than numbers or ratios on paper; they reflect the *minimum* number of responsible people needed on duty to safely care for and supervise dependent individuals.

- Do agency policies and training programs ensure that all staff are aware of the minimal staffing requirements and, as important, their duty and the means by which to assure the requirements are met, including contacting on-duty or on-call administrators when their efforts to ensure adequate staffing at the program site are unsuccessful?
- Are potentially hazardous materials securely stored to prevent accidental ingestion? While baking soda is not considered hazardous and is commonly used as a deodorizer, ingested in large quantities, it can be injurious.
- Should an individual ingest a potentially hazardous substance, do agency policies and training efforts ensure that all levels of staff— direct care, supervisors, on-call administrators, etc. — are aware of the importance of securing medical advice, either from agency medical personnel, a local hospital, or the local Poison Control Center?
- When an on-call administrator, who is not a health professional, becomes aware of a potential medically related event, do agency policies ensure that health personnel are contacted to either personally assess the situation or obtain from staff objective data and advise staff on conditions which should be monitored in order to make treatment decisions?

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 Grace Maddux:
Preventing Accidents During Activities of Daily Living
Case #21

Background

Grace Maddux¹ was born in upstate New York in the mid-1940s. The product of a full-term pregnancy and normal delivery, she progressed through her early developmental stages without difficulty.

However, at five years of age, Grace experienced an unspecified illness accompanied by a high fever. Subsequently, according to her family, things started to change: Grace had "brief spells" of staring into space; she would also become explosive at times, breaking objects in fits of rage followed by deep remorse.

These changes prompted several hospitalizations for testing. Grace was diagnosed as having psychomotor seizures. Grand mal seizures began at age seven, and in addition to a seizure disorder, Grace was diagnosed as having mental retardation.

Grace was initially placed in special education classes in a public school. Soon thereafter, she was placed in a state institution for the developmentally disabled where she lived for the next nearly 30 years.

At 42 years of age, Ms. Maddux was transitioned to a community-based group home. Although severely mentally retarded, Ms. Maddux was semi-independent in most activities of daily living and needed only verbal reminders and occasional physical prompts to tend to her basic needs. She did, however, have an unsteady gait and was prone to falls; in addition, she suffered frequent seizures despite receiving medications to address her convulsive disorder. Her seizure disorder and medication needs were followed closely by a neurologist who monitored her seizure activity, medication regimen and blood levels. Despite receiving anticonvulsants within the therapeutic range, Ms. Maddux's seizure disorder was never well controlled and on average she experienced 11 seizures a month, described variously as drop, grand mal, or complex seizures. There were no known precursors to signal or indicate an impending seizure and Ms. Maddux periodically sustained minor injuries as a result of her seizure activity. Otherwise, she enjoyed good health and attended a day program sponsored by the agency that operated her group home.

The Incident

One summer morning at day program, Ms. Maddux, two other clients and a staff member, Ms. Child, were involved in a project of preparing potato salad for other program participants. They worked together in a kitchen area. The potatoes were peeled and placed in a large pot of boiling water on the stove. While one client washed the utensils, Ms. Maddux washed the kitchen table; the third program participant sat at the table resting. Earlier, Ms. Child, the lone staff member in the room, had sent another client to summon a staff person to relieve her so that she could use the bathroom. Anxiously awaiting relief, Ms. Child walked to the kitchen doorway leading to the hall. Although she never left the kitchen, Ms. Child turned her back to the clients while she looked in the hallway for her relief.

When Ms. Child turned her attention back to the program participants, she saw Ms. Maddux leaning over the stove with her face in the large pot of boiling potatoes. Almost simultaneously, one of the other clients screamed, "Grace is having a seizure."

Ms. Child rushed toward Ms. Maddux, lifted her face from the boiling water and lowered her to the floor on her back while cradling her head in her own lap. Ms. Maddux was obviously having a seizure. Ms. Child also started screaming for help and other staff responded and placed cold wet towels on Ms. Maddux's obviously burned face. Emergency medical services were also summoned.

As Ms. Maddux came out of her seizure state, she started screaming and tried to scratch her face; staff held her arms and attempted to calm her.

¹ A pseudonym.

The ambulance squad arrived within minutes and Ms. Maddux was taken to a local hospital, then airlifted to a regional burn unit where she was diagnosed with second- and third-degree burns to her face, neck, ear, mouth and tongue. The next day Ms. Maddux underwent procedures to place tracheostomy and gastrostomy tubes to assist breathing and feeding.

Within one week her condition was sufficiently stable to undergo skin grafting procedures under general anesthesia, to which Ms. Maddux's family consented. However, during surgery, Ms. Maddux experienced cardiac arrest, was revived once, but then succumbed.

Investigation Results

Investigations into the events leading to Ms. Maddux's death concluded that she accidentally suffered severe facial burns when she experienced a seizure while momentarily unsupervised during a cooking program. Re-enactments of the day's events indicated that Ms. Maddux most likely suffered a drop seizure, falling face first into the pot of boiling water — the burn patterns were consistent with such a fall; the pot, given its size, shape and weight when filled with water and potatoes, would not be displaced by such a fall; and based on staff and client statements (which were largely consistent) about Ms. Maddux's responses, it appeared she had experienced a seizure (i.e. she did not react to the boiling water or attempt to pull away; she became responsive only after being removed from the water by staff and cradled on the floor for several moments.)

Re-enactments also indicated that Ms. Maddux's accident could have occurred in as little as ten seconds of unsupervised time.

Had the pot of boiling potatoes been covered, or had the pot been placed on one of the stove's back burners (as opposed to a front burner), or had a staff member been stationed near the stove while it was in use, Ms. Maddux's injuries could well have been avoided, according to investigators.

Furthermore, the investigations revealed that there was no clear expectation as to what level of supervision Ms. Maddux required. Treatment records referenced Ms. Maddux's frequent seizures, unsteady gait and falls, and resulting injuries. They also referenced her need for heightened supervision, but not in explicit or clearly understood terms.

For example, one record entry stated, "[Ms. Maddux] needs to have at least visual supervision at all times due to seizure activity." Another stated she needs "constant supervision due to seizure activity." Elsewhere it was stated "she should not be left alone . . . due to seizure activity." These comments on supervisory needs were not addressed in behaviorally specific or universally understood terminology, such as: Ms. Maddux needs to be within arm's reach of staff; or she needs to be in line of sight of staff at all times; or staff, while not needing to visually monitor Ms. Maddux, need to know of her location or be close to her. Consequently, Ms. Maddux's supervisory needs were interpreted differently. While some staff felt she needed to be within sight at all times, others — including day program staff on the day of the incident — felt it was sufficient to just know her location, which they did; but in the ten seconds or more that a staff member's back was turned, tragedy struck.

Outcomes

As a result of the investigations, the agency established certain rules for kitchen use safety, namely: whenever pots are in use on the stove, they will be covered; to the extent possible, stove back burners will be used to reduce the likelihood of accidental contact with more easily accessible front burners; and whenever a stove is in use, a staff member will remain near it if any program participants involved in the activity require supervision.

Additionally, the agency required that all its staff receive training in kitchen safety issues.

The agency also embraced recommendations to ensure that treatment team recommendations regarding client supervision are stated in behaviorally explicit terminology and are communicated and understood by all parties (i.e., residential habilitation and day habilitation staff) involved in the client's care.

Finally, the agency took steps to formalize a system of relief for staff involved in programs who need lunch, bathroom, or other breaks from their activities.

Lessons Learned

This writer worked for four years in a day program for developmentally disabled adults in which meal preparation was a daily event. Thankfully, never did I encounter an experience paralleling Grace Maddux's; nor have I encountered one in the past two decades working as an investigator.

Could any person have reasonably predicted Ms. Maddux's seizure and fall into a pot of boiling water during such an activity? I doubt it. Nevertheless it happened. Upon recovering from her seizure, her last days were painful, until death offered relief. To this day, the staff who served her and her family are pained by the remembrance of her last days and her loss.

The circumstances surrounding Ms. Maddux's death offer lessons to assist others in preventing what may appear to be an unpredictable event, and the pain to all surrounding it.

Does your agency, in its policies and practices:

- Ensure clear, behaviorally explicit expectations concerning the level of supervision required by program participants? If you serve individuals whose primary care is provided by another agency or group, is there a common understanding of the supervision needs of the individuals served? Are all staff who interact with the individuals served aware of their supervision needs?
- Establish safety standards surrounding the use of kitchens which address such issues as stove usage, protection of individuals from heat sources, adequate supervision while stoves or other potentially dangerous appliances are in operation?
- Provide regular staff training or refresher courses in consumers' needs for supervision and kitchen and other safety measures?

Finally, recognizing from this case the predicament of a sole staff person requiring relief from his or her duties, does the agency have in place a formal system to ensure prompt relief where indicated?

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 Sara Grand:
Preventing Deaths by Timely Medical Care and Monitoring
Case #22

Background

Sara Grand¹ was 42 years old when she died in her community residence on Long Island, New York.

Ms. Grand had lived in the group home for nearly a decade. Diagnosed as having chronic undifferentiated schizophrenia and mild mental retardation, Ms. Grand's stay in the home was without major incident. Although hospitalized for psychiatric reasons prior to her admission to the group home, she did not require inpatient psychiatric care in the years that followed. And aside from periodic bouts of bronchitis and minor stomach bloating, apparently due to constipation, Ms. Grand's medical history was unremarkable. Slightly overweight, Ms. Grand was also a cigarette smoker. Over the years, Ms. Grand was maintained on a regimen of antipsychotic and antianxiety medications prescribed within normal limits for her psychiatric difficulties; her problems with constipation were addressed through diet and the administration of stool softeners.

While living in the community residence, Ms. Grand attended a day program five days a week. Habilitation goals focused on increasing her socialization skills (she tended to be reclusive and to stay in her room reading or writing); promoting independent living skills, such as self-medication, doing her own laundry, and managing her money; and maintaining a healthy diet. Ms. Grand was essentially proficient in most activities of daily living, but needed verbal prompts and reminders. The ultimate goal was for her to transition to a more independent living situation, as opposed to one which had 24-hour-a-day supervision.

The Incident

On the Friday just before Christmas, Ms. Grand returned home from her day program. Nothing unusual was noted in her progress notes. However, according to medication records, Ms. Grand was given Tylenol because she was complaining of a headache.

On Saturday morning, Ms. Grand woke up and complained of not feeling well. There are no progress or house log notes about her complaints, but according to day-shift staff, Ms. Grand complained of chest and back pains, headaches, and blurred vision; she ate very little, appeared tired and pale, and had dry lips. Ms. Grand stated that she felt like she had the flu, which a number of the home's residents had recently had. Vital signs were taken and, although not documented, were reportedly normal.

The house manager, who worked the day shift, instructed oncoming evening-shift staff to watch Ms. Grand carefully and to send her to an emergency room if her symptoms worsened.

As Saturday evening progressed, Ms. Grand continued to complain of headaches, blurred vision, chest and back pain, and an upset stomach. She complained of feeling hot, and then cold. Her appetite was off, and she spent a great deal of time sleeping on the couch or in her room.

One of the evening staff who happened to be a licensed practical nurse by training, but not employed in that capacity, believed Ms. Grand's symptoms may have been medication-related. She was of the opinion that Ms. Grand's evening medications should be held; other staff deferred to her judgement as she was a nurse. Ms. Grand also agreed.

The staff member documented this decision and Ms. Grand's symptoms and vital signs: Temperature 99°, Pulse 72, Respiration 18, and Blood Pressure 130/80.

The staff member also attempted to "beep" the on-call administrator once at approximately 8:00 p.m., but received no response. (At 8:30 p.m., the on-call administrator discovered her beeper was in the "off" mode and turned it on.) Not hearing from

¹ A Pseudonym.

the administrator, the staff member called the off-duty residence manager and assistant manager. Neither was home, so she left messages on their answering machines, asking that they call her.

The staff member also called staff at one of the agency's other community residences to report her concern that Ms. Grand may have been having a medication reaction. Staff advised her to call Poison Control. She didn't; she didn't believe the situation was that serious.

The staff member then left the facility, having been relieved by the midnight-shift worker.

According to this staff member, Ms. Grand was up all night, complaining of not feeling well. By this time, Ms. Grand was having difficulty walking and talking; she complained of a headache and ringing in her ears; at one point she was found in the bathroom attempting, unsuccessfully, to vomit. The staff member took her blood pressure (100/70), but took no temperature and could not ascertain Ms. Grand's pulse rate.

The staff member tried to call the off-duty residence manager and assistant manager. With no one answering, she left messages on their machines, reporting that Ms. Grand was sick. She did not attempt to reach the on-call administrator, as policy required.

When questioned why she did not send Ms. Grand to a hospital, given the client's symptoms and the absence of supervisory guidance, the staff member gave several different reasons: first she stated she didn't believe the situation was that serious; then she indicated that if there had been a second staff member on duty to watch the other nine residents, she would have taken Ms. Grand to the hospital herself in her own car. She also pointed out, while stating she didn't want to lay blame, that the previous shift had an LPN on duty (who was presumably more knowledgeable), and they did not initiate hospitalization; she essentially followed their lead.

At about 8 a.m. Sunday morning, Ms. Grand reported for her morning medications; she appeared tired and complained of being feverish.

Shortly thereafter, the house manager and assistant manager called the home in response to the messages left on their machines during the past 12 hours.

A day-shift staff member answering the phone, who had seen Ms. Grand up and about earlier at medication time, reported that there were no problems. Apparently during these conversations, Ms. Grand's symptoms of the previous 24 hours were not discussed, nor was there an assessment requested or a discussion of her current clinical condition.

As Sunday progressed, Ms. Grand did not want to eat, she complained of feeling feverish and in pain, and she wanted to just stay in bed. When the staff member who had earlier told the house manager and assistant manager that there were no problems learned of Ms. Grand's symptoms, he tried to call back both. This was around noon. He reached the assistant manager first and reported that he may have spoken prematurely when he reported no problems earlier. Ms. Grand appeared ill and staff were concerned.

The assistant manager instructed staff to take Ms. Grand's vital signs. But when they went to do so, she was found unresponsive in bed. Emergency medical services were summoned, but Ms. Grand could not be revived. The cause of death determined upon autopsy was pneumonia, a condition which may have been remedied with timely medical intervention.

Outcome

The agency's investigation into Ms. Grand's demise revealed a number of shortcomings in the care provided her in the days prior to her possibly preventable death, shortcomings which crossed shifts and muddled the picture of how sick Ms. Grand was and how staff should have responded.

- Neither the residence log nor Ms. Grand's record provided a clear picture of the onset, persistence, and worsening of her symptoms.
- Instructions from the house manager to seek hospitalization if symptoms became worse were not posted in Ms. Grand's record or the house log; nor were they communicated verbally from shift to shift.

- A licensed practical nurse made diagnostic and treatment decisions which she was not credentialed to do, decisions which influenced others' actions.
- Staff made diligent efforts to contact off-duty supervisors over a more-than-12-hour period; however, these off-duty supervisors were not home. And while staff tried once unsuccessfully to "beep" one on-call administrator, they did not try to beep her again or to beep other senior staff who were on call.
- When off-duty staff eventually responded to messages on their answering machines, Ms. Grand's true condition was not well communicated because it was not clear to Sunday morning-shift staff, based on the limited record entries of previous shifts, and was not directly assessed at that time on Sunday morning.

Based on its findings, the agency initiated several corrective actions. In addition to disciplining some staff, the agency re-educated staff on documentation standards, on-call procedures, and monitoring signs and symptoms of illness. The agency also instituted an on-call nursing rotation so that a nurse will be "on beeper" at all times. Finally, the agency reinforced with all staff that they have the authority to call 911 or EMS immediately if they believe a resident requires medical attention.

Lessons Learned

Far too often, the Commission has seen cases wherein staff were instructed to "watch" an ill individual, which they dutifully did as the individual's life ebbed away needlessly. Such cases prompted the creation of this series;² Sara Grand's case illustrates that there are lessons still to be learned, repeated, and reinforced.

To what extent do your agency's policies and training efforts:

- Ensure recordkeeping and shift-to-shift communication practices which promote a clear picture of changes in an individual's health or behavioral status?
- Prescribe what staff should look for or assess and how to assess it, when they are told to "carefully watch" an ill individual?
- Guarantee a clear and universally understood line of communication with on-call senior staff — including medical professionals — should situations arise during "off" hours?
- Authorize and empower direct care, and largely nonmedical, staff to call 911 or emergency medical services when an individual appears persistently or critically ill and in-house advice/assistance cannot be obtained?

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?

² *In the Matter of Mary Rose, and In the Matter of Mildred Thomas.*

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 Gail Foster:

Dealing with Crime In A Residential Program

Case #23

Introduction¹

When the police arrived, hospital staff began to appreciate the seriousness of the situation—something they had avoided confronting for the several hours since they learned of the incident which now brought the police.

Five patrol cars drove onto the hospital grounds. While some police officers went through rooms interviewing staff and patients, confiscating bed sheets and reading shift logs, others attempted to calm or control the boys and girls on the adolescent unit who were disturbed by the alleged rape of one of their peers.

The police arrived, not at the request of hospital staff, but in response to one patient who used a pay phone to report the rape after staff told her the matter could wait until the next day.

When the police left, they did so with two boys from the unit who subsequently pled guilty to misdemeanor sex offenses. The 15 year old victim was escorted to a community hospital for a proper medical examination, more than five hours after she disclosed her molestation.

Even after the magnitude of the situation became apparent, the hospital's response failed to measure up: the facility filed an incident report and commenced an investigation *the next day*. In spite of some facts, and absent others, the facility concluded that there was no evidence to suggest the victim was not a willing participant, that she (the victim) "poses a problem for herself and male patients," and that the incident revealed no area of hospital operations "requiring extra scrutiny:" staff conduct was "exemplary."

The Incident(s)

At approximately 2:30 one winter afternoon, Ray Backman, one of the 18 patients housed on the hospital's adolescent unit, approached the unit nurse. He requested to see his therapist. Mr. Backman indicated that he was feeling guilty about having had sex with Gail Foster, another adolescent on the unit, earlier that day (some time before 1:30 p.m.). He reported that another adolescent, Josh Cote, also had sex with Ms. Foster. The nurse advised Mr. Backman that this was a matter he should discuss with his therapist in a private session, either later that day or the next day.

Almost simultaneously, another patient, Charlie Able, approached a nurse's aide, Ms. Devon, and reported that he had witnessed Ms. Foster having sex with Mr. Backman and Mr. Cote in the boys' bedroom/bathroom area. Ms. Devon informed the unit nurse and then confronted Ms. Foster in Mr. Able's presence.

Ms. Foster— who was 15 years old and diagnosed as having paranoid schizophrenia and borderline intelligence — indicated that she had been in the boys' room as Mr. Able reported. However, she claimed they were playing hide and seek. Ms. Devon recounted what Mr. Able reported to her and asked Ms. Foster, "Are you calling Mr. Able a liar?"

At this point, Ms. Foster confided that she had engaged in sex with both Mr. Backman and Mr. Cote. But she indicated she was forced to do so.

In short order, Ms. Devon gathered all four young patients together — Ms. Foster, Mr. Able, Mr. Backman and Mr. Cote — to discuss the incident. Mr. Cote admitted that he forced Ms. Foster to perform oral sex on him in the bedroom/bathroom area by grabbing her by the neck and head. With a "so what" attitude, he claimed he had done the same thing to his little sister and that his stepfather had sexually abused him. Mr. Backman admitted he had sex with Ms. Foster after Mr. Cote did; he denied that he used force, but

¹ All names are Pseudonyms.

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 Linda Simon:

Despite Late Reporting, The Incident Review Process Works

Case #24

Introduction

Thursday evening was not unlike most evenings in Linda Simon's¹ group home. Five staff were on duty assisting the 11 residents in their usual pre-bedtime routines: the shift supervisor was administering medications while the other direct care staff tended to the residents' bathing, toileting, clothes-changing and other basic needs.

Most of the residents, including 26 year-old Ms. Simon, were nonverbal, nonambulatory, functioned in the severe to profound range of mental retardation, and were totally dependent on staff assistance in activities of daily living.

Two of the staff on duty, Ms. Cancer and Ms. Runkler, were relatively new to the agency and to their duties in the home. One, in fact, was "on loan" to the house from one of the other homes run by the agency.

The Event

At approximately 8:00 p.m., the shift supervisor asked Ms. Cancer to give Ms. Simon a bath. This required the use of a lift to transfer Ms. Simon from her wheelchair to the tub. Ms. Runkler helped Ms. Cancer with the transfer.

While staff bathed Ms. Simon and washed her hair, she offered no complaint. When she was done being bathed, however, Ms. Simon had a toileting accident in the tub. Staff promptly decided to remove her from the tub. They readied the towels to dry her and then attempted to refasten the lift's harness around Ms. Simon in order to remove her from the tub.

Ms. Cancer and Ms. Runkler had difficulty positioning the harness, a part of which kept riding up between Ms. Simon's legs. When they thought it was properly positioned, they attempted to move Ms. Simon from the tub's dirty water.

But as Ms. Simon was hoisted in the harness, she began to cry out in pain. Staff immediately stopped the procedure and then noticed blood between her legs.

Ms. Runkler went to the shift supervisor and reported difficulty in removing Ms. Simon from the tub; she requested assistance, but did not mention the blood or that Ms. Simon may have been injured.

Still busy with medications, the shift supervisor advised Ms. Runkler to seek out another staff person for assistance, which she did.

The third staff person, Ms. Gale, upon entering the bathroom, noticed that the harness was improperly positioned on Ms. Simon. She also noted some blood in the tub as well as the feces. Ms. Gale secured a new, clean and dry harness and, with the help of Ms. Cancer and Ms. Runkler, secured Ms. Simon in it and removed her from the tub. Ms. Gale alerted the shift supervisor that she had noticed blood in the tub and around Ms. Simon's vaginal area; Ms. Gale, however, was not sure where the blood came from. (It should be noted that Ms. Simon had had her period very recently; in fact, when Ms. Gale changed her diaper the day before, she noticed a small amount of blood in it.)

While direct care staff went about other tasks, the shift supervisor checked on Ms. Simon who was now in bed. She noticed that Ms. Simon's labia were swollen and red and that there was some bloody discharge.

Treatment

The shift supervisor reported her observations by phone to both the on-call nurse and the on-call physician. Both the nurse and the physician agreed that Ms. Simon, who had a history of vaginitis and yeast infections, was probably suffering from such an infection. They instructed the shift supervisor to begin treatment with Terazol cream, for which Ms.

¹ All names are pseudonyms.

Simon had a PRN order due to her frequent infections. The physician also asked to see Ms. Simon, if her condition remained the same or worsened.

Over the next nearly 48 hours, Ms. Simon received treatment for a suspected yeast infection. No active bleeding was noted and the swelling appeared to diminish.

A Revelation

On Saturday afternoon, Ms. Runkler – who had assisted in the improper placement of the harness on Ms. Simon on Thursday evening, heard Ms. Simon's screams as she was being lifted from the tub, and then saw that she was bleeding – mentioned to co-workers that perhaps Ms. Simon was injured during the lift procedure and was not suffering from a yeast infection.

This information was relayed to supervisory staff, nurses and the physician. Subsequently, Ms. Simon was examined by the physician and found to have a 3 centimeter laceration on the inside of her vulva. The laceration appeared to be healing well and there was only minimal swelling. Ms. Simon's Terazol cream treatments were stopped and she was started on an oral antibiotic.

According to the physician who examined Ms. Simon, the shift supervisor who initially examined Ms. Simon on Thursday evening could not be faulted for missing the laceration given its location and the fact that the supervisor was not familiar with Ms. Simon's anatomy and was unaware that she had suffered a trauma.

Investigation Results

Investigations into the events of that Thursday evening revealed that Ms. Simon was indeed injured when staff failed to properly secure her in the lift and attempted to hoist her from the tub. The improperly positioned harness had lacerated Ms. Simon's vulva. Aware that Ms. Simon was most likely injured, these staff failed to inform their supervisor of this possibility. However, it was also found that these staff had not been trained in how to operate the lift used to transfer Ms. Simon; and that on the Thursday night they were instructed to use the lift, they asked the supervisor for assistance, not once but several times, and received little help.

Furthermore, it was found that when one of the staff responsible for the injury eventually realized that Ms. Simon was being treated mistakenly for a yeast infection, she fully reported the events of the past Thursday evening. As a result, Ms. Simon was properly diagnosed and treated.

While concluding that Ms. Simon was accidentally injured at the hands of staff, the facility concluded that the circumstances of her injury, and the handling of such, reflected more on problematic systemic issues – such as training and supervision of staff and incident/event reporting – than the conduct of specific staff in this particular incident. Rather than instituting disciplinary action, the agency focused its corrective measures on providing new and "relief" staff better training and enhancing staff supervision.

Lessons Learned

The success of any incident management system rests first and foremost on its use: will staff report untoward events? The examination and prevention of untoward events requires their reporting in the first place, and reporting practices are shaped largely by the outcome or fallout, real or perceived, of past reports.

Consider this:

On one hand, on the surface, it would appear that Ms. Simon sustained a painful injury at the hands of careless staff. Over the years, the Commission has seen similar scenarios in which the staff involved were summarily fired, without question, without chance to explain. On the other hand, Ms. Simon's injury, though misdiagnosed and mistreated as a yeast infection, was healing and could have gone undetected with no lasting negative impact beyond her initial pain. All staff would have retained their jobs and business would have continued as usual. (Over the years one can be sure that similar scenarios have slipped by agencies and the Commission as well.)

But in Ms. Simon's case staff spoke up, albeit late, about their role in possibly causing an injury. This paved the way for Ms. Simon's proper diagnosis and treatment. More importantly, it exposed shortcomings in the agency's overall practices relative to staff training and supervision – practices which set staff up for failure in the first place, and put Ms. Simon in harm's way.

As a result of staff's confession or report, and the agency's measured response, all staff are receiving the training they require and no client is being placed in the vulnerable position Ms. Simon was. And, hopefully, the value of the incident reporting and remediation process has been underscored and reinforced for all parties.

Ms. Simon's story should give pause to all agency heads and their staff to reflect on the value, fairness and utility of their own incident management systems. What steps can be taken to ensure that:

- All staff are aware of their incident reporting responsibilities? While staff are usually trained to immediately report incidents, are staff encouraged to report incidents even after they occur, once they become cognizant that such may be reportable events?
- Investigations go beyond individual staff behaviors and probe matters which may shape those behaviors such as supervisory practices, training issues, agency policies and longstanding practices/traditions?
- Investigation outcomes, be they disciplinary measures or other corrective actions, are commensurate with the problems they are intended to remedy or prevent?
- All levels of staff are aware of the outcomes of incident investigations and can see their role – as reporters, investigators, witnesses, and, most important, implementors of remedial actions – in this problem solving process? Oncoming shift staff were made aware of the incident. They decided to inform the Medical Director after the 6:00 p.m. patient community meeting; it was planned that the incident would be the focus of the meeting.

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 Amos Grace: *Are Professional Staff Above Reproach?*

Case #25

Background

Amos Grace¹ was born in New York City just prior to World War II. The product of a full term, uncomplicated pregnancy and normal delivery, he appeared to be a healthy baby. In time, however, it was noticed that his language development was severely delayed and it was believed he was hearing impaired.

As a youngster, Amos attended a "school for the deaf" for two years. But he was discharged, as the school was "not able to get any response from him;" it was felt he suffered from a mental disability.

For the next 10 years, Amos lived at home. He did not attend school and was cared for by his mother while his father worked.

In the late 1950s, Amos Grace's mother became ill and was unable to care for him. Then a young adult, Mr. Grace was committed to an institution for individuals with mental retardation. He resided there for the next nearly 40 years.

Mr. Grace was diagnosed as having severe mental retardation. Although nonverbal, he was able to express his likes and dislikes through facial expressions. He was also ambulatory and very active in the facility's programs. He particularly enjoyed nature walks and outdoor activities. At 57 years of age, Mr. Grace was in generally good health, semi-independent in many activities of daily living and required no medications.

The Incident and Facility Review

At approximately 1 o'clock on a winter morning, Mr. Grace left his bedroom to use the bathroom. Upon finishing in the bathroom, Mr. Grace started walking back to his room. Suddenly, he fell forward striking his chin on the floor. Two staff witnessed the fall, and according to their statements to the facility investigator, Mr. Grace made no attempt to break his fall by extending his arms. (It was felt he may have had an episode of bradycardia or syncope.)

Staff rushed to Mr. Grace's aid. He did not lose consciousness. However, he was bleeding from the mouth and chin and it appeared that he lost at least one molar.

Mr. Grace was promptly sent to the infirmary where a physician placed three stitches in the chin. The physician noted that Mr. Grace had normal vital signs, but some dried blood in his left ear, which he cleaned. Noting also the missing molar, the physician scheduled Mr. Grace to be seen in the dental clinic when it opened at 8:00 a.m. Mr. Grace was returned to his ward at about 2:00 a.m.

According to the facility's investigation and Special Review Committee (SRC) meeting minutes, Mr. Grace was seen in the dental clinic where the dentist consulted with the facility Medical Director, and it was decided to send Mr. Grace to a local hospital for further evaluation. At the hospital, according to the SRC, Mr. Grace was diagnosed as having "a fracture of the jaw, small tear to the eustachian tube, laceration to the tongue and possible fractured skull." The SRC and Medical Director concluded Mr. Grace received appropriate care both at the facility and while in the hospital.

With that determination, the facility closed its investigation. And closed it would have stayed, filed away with hundreds of other closed investigations, had it not been for an astute certification surveyor who requested the Commission's review of Mr. Grace's medical care at the facility.

The Commission's Investigation

Consistent with the facility's investigation, the Commission found that Mr. Grace fell to the floor, possibly as a result of bradycardia or syncope, and was promptly sent to the infirmary where several stitches were placed in his chin and arrangements were made for him to be seen later in the dental clinic.

¹ All names are pseudonyms.

Not touched upon by the facility's investigation, however, was the fact that the infirmary physician, while noting blood in at least one of Mr. Grace's ears – a sign of possible serious head injury or skull fracture – did not send Mr. Grace to a local hospital for further evaluation; he did not feel it was necessary. Nor did the infirmary physician order frequent vital sign monitoring for Mr. Grace, a routine procedure for head trauma patients. Rather he gave Mr. Grace two Tylenol and sent him back to his unit to await the opening of the dental clinic.

Also omitted from the facility's review of the incident was a detailed analysis of the events preceding Mr. Grace's hospitalization.

Upon return to his unit, Mr. Grace was put to bed. After a period of yelling, he eventually fell asleep.

When Mr. Grace awoke several hours later, his tongue was swollen, protruding from his mouth, and staff could see a severe laceration. He was taken to the dental clinic and was seen at approximately 8:00 a.m.

The dentist noted blood in both of Mr. Grace's ears, three broken or missing teeth and a severe tongue laceration. Mr. Grace appeared to be in pain and was uncooperative, making a thorough examination difficult. Hearing the history of the fall and observing Mr. Grace's condition, the dentist suspected severe head trauma and possible fractures. He immediately called the facility's Medical Director and suggested that Mr. Grace be transferred to the local hospital.

The Medical Director, however, informed the dentist that the transfer could wait until Mr. Grace's primary physician reported for duty and completed the necessary paperwork. The Medical Director ordered Mr. Grace to be sent back to his unit to await the arrival of his regular doctor.

Nurses on the unit informed the Commission that they called the Medical Director and "begged" that Mr. Grace be sent to the hospital immediately. They pointed out that his regular physician would not be on duty for at least another two hours. The Medical Director was not moved by the pleas.

As such, one of the nurses took it upon herself to call Mr. Grace's primary physician, who was off duty and at home, and explain the situation. He gave permission for Mr. Grace to go to the hospital and the nurse transported him in a facility van.

Mr. Grace arrived at the hospital at 10:00 a.m. Whereas the facility's Special Review Committee minutes indicate that Mr. Grace was diagnosed as having a fracture of the jaw, small tear to the eustachian tube, a tongue laceration and possible skull fracture, hospital records revealed the full extent and seriousness of his injuries:

- several fractured teeth;
- five fractures to the jaw, skull, and neck bone;
- a laceration to the tongue requiring 35 sutures; and
- a torn eustachian tube and bleeding from both ears.

Due to the "huge," as hospital staff recorded it, swelling of the tongue, Mr. Grace required a tracheostomy in order to maintain an airway. He was admitted to the Intensive Care Unit and underwent extensive surgery to repair his fractures and injuries. Mr. Grace was hospitalized for nearly one month, and two additional months passed before he was fully recovered and back to his "usual self." Hospital staff were alarmed that more than nine hours passed between when Mr. Grace was injured and when he was brought to the hospital.² The swelling associated with his injuries had placed him at risk of life-threatening respiratory distress.

Discussion

Mr. Grace was rescued from the consequences of potentially life-threatening injuries and over nine hours of pain and suffering not through the intervention of physicians, but through the initiative of a nurse. Whereas an infirmary physician ignored obvious signs and symptoms

² Medical experts consulted during the investigation agreed that the nature of Mr. Grace's injuries were consistent with a fall to the floor and did not suggest physical abuse. Medical work-ups, however, failed to explain why Mr. Grace collapsed to the floor.

of severe head trauma and the Medical Director, aware of the injuries, was content to allow the matter to wait a couple more hours, the nurse took matters into her own hands and arranged for Mr. Grace to receive the medical attention he needed.

In its investigation report, the Commission commended the nurse for her actions. It also called for licensing agency review of the infirmary physician and Medical Director whose performance in this case (or lack thereof) appeared to constitute neglect. (The Medical Director promptly retired and the infirmary physician was disciplined.)

The case of Amos Grace, however, illustrated a more fundamental problem than the poor performance of two individuals, and that is the failure of a facility to honestly critique the actions of its professional and administrative staff.

When untoward events involving service consumers occur, the role and actions of direct care staff understandably are carefully examined. After all, it is the direct care staff who are on the front lines of service delivery. But too often, the scrutiny ends there, and there is no review of the role of professional staff or facility policies or practices which may have played a part in the incident.

Such occurred in the case of Mr. Grace. Once the facility ruled out the possibility he had been physically abused on his unit, it neglected to explore why a severely injured individual did not receive necessary medical care for more than nine hours. In fact, minutes of the facility's SRC seem to indicate that this aspect of care was purposefully omitted from review. The minutes appear to downplay the extent and seriousness of Mr. Grace's injuries. And when one committee member broached the topic of the timeliness of medical care, the minutes indicate that the Medical Director (who sits on the committee – a clear conflict of interest in this case) reported that he personally reviewed the conduct of the infirmary physician and found no problem.

Absent a critical review of professional staff's role in this incident, the facility failed to recognize the life-saving value of its nursing staff and the coldhearted indifference, if not incompetence, of certain medical staff.

Mr. Grace's case provides program operators and staff an opportunity to reflect upon what steps they may need to take to ensure that:

- Staff are empowered to take action or go to higher authorities when they are given instructions which they sincerely believe are not in a consumer's best interest, may harm the consumer, or deprive him or her needed services;
- Investigations of untoward events fully examine the actions of professional/administrative staff as well as direct care staff in incidents and to what extent policies or standard operating procedures may have played a role;
- Special (or Incident) Review Committee membership and deliberations are not prejudiced by conflicts of interest; and
- Staff who perform in an exemplary fashion receive the positive feedback they deserve as quickly as problematic performance is brought to one's attention – an important element of program management too frequently overlooked.

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 Joan Stalker:

Too Little, Too Late

Case #26

Introduction

When 50 year-old Joan Stalker¹ died in her family care home, it was initially reported that she had suffered a massive heart attack. Upon autopsy, however, it was discovered that she had serious underlying medical conditions which may have been neglected; she also had numerous bruises suggestive of physical abuse.

This was not the first time abuse was suspected in the home where Ms. Stalker lived. Nearly two months before Ms. Stalker's death, another resident of the home claimed she was abused by her care provider, prompting an investigation by the state agency which certified the home. The investigation results, which indicated misconduct, however, were not shared with the agency sponsoring the home until three months after Ms. Stalker's death, and offered too little, too late.

Background

Family care is one of the oldest community-based care modalities in New York State. Natural families are certified by either the State Office of Mental Health (OMH) or the State Office of Mental Retardation and Developmental Disabilities (OMRDD) to provide residential care and other services to individuals with mental disabilities. Family care homes are "sponsored" by not-for-profit agencies serving people with disabilities or by the state certifying agency. Staff of the sponsoring agency offer training and assistance to the family care provider and visit and inspect the home monthly to assure it meets standards and the consumers are well cared for.

Joan Stalker was 49 years old when she and three other disabled women moved into the Wayne family care home. The move was precipitated when the operator of the family care home in which the women had been living developed difficulties meeting standards and surrendered her operating certificate. The new home into which the women moved, Ms. Wayne's, was certified by the OMRDD and sponsored by a not-for-profit agency which ran a variety of programs for children and adults with emotional difficulties or mental retardation.

Ms. Stalker, like her housemates, functioned in the moderate to mild range of mental retardation, and was ambulatory and verbal. All four women seemed to adjust well after the move and were able to attend their same day programs.

Trouble in the House

Seven months after Ms. Stalker and her housemates moved into the Wayne family care home, one of the women boarded her bus for day program in tears. She reported to the driver that Ms. Wayne had slapped her in the face and pushed her down. She had a bruise above her eye and the eye was slightly swollen; she also had bruises on her hand and elbow. The client repeated her accusation to staff at her day program who relayed the information to the agency sponsoring the Wayne family care home.

The client refused to go back to Ms. Wayne's home as she was afraid because Ms. Wayne told her not to tell anyone about the incident. An alternative placement was found for the client and the sponsoring agency requested that the state certifying agency investigate the allegation of abuse.

During the investigation, two of the female residents of the family care home—including Ms. Stalker—denied any knowledge of Ms. Wayne striking the injured resident. The third client reported that Ms. Wayne had pushed the injured client, causing her to fall.

Ms. Wayne, herself, initially reported on interview that nothing had happened. On a subsequent interview, however, she indicated that she had argued with the client about getting ready for day program and that the client tripped and fell. Ms. Wayne, however, said that the client did not appear hurt as she (Ms. Wayne) escorted her to the bus. Contradicting Ms. Wayne's version, the bus driver claimed that Ms. Wayne did not escort the client to the bus and that the client had obvious injuries and was distressed.

¹ All names are pseudonyms.

The certifying agency investigator completed his investigation within two weeks of the allegation. He concluded that Ms. Wayne did not strike the client but had taken "some action" to cause her to fall and be injured; further, he concluded, Ms. Wayne did not treat the obvious injuries or notify the sponsoring agency of the incident, as required. The conclusion was tantamount to a finding of neglect.

The investigator, however, did not share his report with the sponsoring agency until four months later; and the sponsoring agency did not itself investigate the allegation; rather, it waited for the certifying agency's report. In the interim Ms. Stalker became ill and died.

Ms. Stalker's Death

About six weeks after the allegation of abuse in the Wayne family care home was raised, Ms. Stalker arrived at her day program unable to bear weight on her left leg. Staff contacted Ms. Wayne and advised her to take Ms. Stalker to a physician, which she did the next day.

Ms. Stalker was diagnosed as having a heel spur and plantar fasciitis, an inflammation of the sole of her foot. The physician ordered special shoes and an anti-inflammatory agent for Ms. Stalker. A follow-up visit was scheduled in ten days. That afternoon, Ms. Wayne notified her sponsoring agency about the doctor's visit, Ms. Stalker's condition, and the fact that Ms. Stalker was refusing to walk, even to the bathroom. Staff of the sponsoring agency promptly visited the home and Ms. Stalker.

Ms. Stalker seemed in good spirits and agreed to ambulate, at least to the bathroom. Ms. Wayne agreed to keep sponsoring agency staff aware of Ms. Stalker's progress and the staff left. It was the last time they saw Ms. Stalker.

Several days later, Ms. Wayne called the sponsoring agency. She reported that she had rented a wheel chair to help Ms. Stalker get around the house. She also reported that Ms. Stalker was doing well but would be held back from day program until the follow-up doctor's visit in five days:

On the morning of the scheduled follow-up visit, however, Ms. Stalker suddenly collapsed; she had no vital signs. Emergency Medical Services were called, but Ms. Stalker could not be revived.

Autopsy and Investigation Findings

Upon autopsy, it was determined that Ms. Stalker died of multiple acute pulmonary emboli due to deep vein thrombosis of the left leg. The autopsy also revealed numerous bruises of various sizes and ages - with the oldest being about one week old - to the chest, abdomen, back and thighs: areas typically hidden by clothing. Additionally, it was found Ms. Stalker had been suffering from acute hemorrhagic cystitis, an inflammation of the bladder so severe as to cause bleeding. The bladder, according to the pathologist, looked like "raw meat."

Concerned about abuse, the pathologist alerted the sponsoring agency; but the agency did not conduct an investigation. The autopsy results were shared with the Commission which commenced an investigation.

During the investigation Ms. Wayne gave several conflicting statements which undermined her credibility and raised many questions about the last 10 days of Ms. Stalker's life. Concerning the bruises, for example, Ms. Wayne claimed that she never noticed them, although she stated she gave Ms. Stalker bed baths. Then she claimed the bruises were the result of Ms. Stalker falling frequently as she ambulated around the house. And yet in another interview, Ms. Wayne claimed that Ms. Stalker fell only once, the day of the initial doctor's visit, and was bed bound for the next 10 days.

Concerning the cystitis, Ms. Wayne, who was a nurse, claimed that she noted bleeding but thought Ms. Stalker was having her period. She also claimed Ms. Stalker voiced no pain. (Clinical records indicated that Ms. Stalker frequently voiced complaints during her menses). Commission nurses found Ms. Wayne's statements on this matter incredible.

Upon interview, the two clients remaining in the home reported that they did not see Ms. Stalker abused as she spent most of her time in her final days in her room. However, they stated that when they were "bad" Ms. Wayne forced them to sit on the floor in corners of the living room.

The Commission shared its findings with the state certifying agency and the agency sponsoring the Wayne family care home; the home was closed and the clients relocated.

Discussion

At a minimum, it is clear, based on client accounts, that Ms. Wayne was a harsh disciplinarian and/or lacked the ability to humanely care and treat developmentally disabled individuals. However, given Ms. Wayne's conflicting statements, it is less clear what transpired in the last week or so of Ms. Stalker's life: Was she abused? Was she mobile but falling frequently and being bruised? Or was she so ill that she was bed bound, and received no medical attention?

What is known with certainty is that Ms. Wayne did not inform her sponsoring agency of Ms. Stalker's frequent falls and bruises (if that is what occurred) or the condition which rendered her bed bound (if that, truly, is how Ms. Stalker spent her final week).

That Ms. Wayne did not seek medical attention for another injured individual in her care or inform her sponsoring agency of the client's injuries – injuries she may have caused – was known long before Ms. Stalker fell ill and died. But it was known to only one individual – the investigator who looked into an earlier allegation of abuse in the household. This investigator's report, although completed before Ms. Stalker's death, was not shared with the sponsoring agency until months later; and the agency, itself, conducted no investigation into that allegation. Consequently, no protective or preventive measures, which may have bolstered supervision of the home and benefited Ms. Stalker, were put in place prior to Ms. Stalker becoming totally dependent on Ms. Wayne for her care.

As a result, the sponsoring agency believed all was fine in the Wayne home and with Ms. Stalker, based on Ms. Wayne's report, despite the fact that a client claimed earlier that she was abused in the home.

Lessons Learned

All certified service agencies have an obligation to protect their charges from harm; a viable incident reporting and investigation system is but one vehicle to fulfilling this obligation.

For Ms. Stalker, the incident reporting and investigation system offered too little too late. By the time her sponsoring agency was informed that months earlier the care provider may have caused injury to another client, failed to report the injury and neglected to care for the injury, Ms. Stalker was already dead, a victim of possible abuse and medical neglect.

In reflecting on this case, care providers should consider the adequacy of their own incident investigation and review systems.

- What actions must the agency take – in terms of reporting practices, reallocation of resources, and staff training – to ensure that it can conduct timely and thorough investigations and implement appropriate preventive measures to protect clients from harm?
- For investigations, does the agency rely too heavily on outside parties whose performance, thoroughness and timeliness are beyond the agency's control? What steps can the agency take to reduce this dependency?
- While perhaps dependent to some degree on an outside agency's investigation/review of an incident, does the agency conduct its own internal investigation to whatever extent possible and initiate corrective or protective actions as soon as the need for such becomes apparent?
- If reliant on outside parties for information relative to an investigation, does the agency actively pursue the information, or is it content to wait, and wait, and wait, as Ms. Stalker's agency did?

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 Sharon Seaver:

Chance Glance Thwarts Suicide Attempt

Case #27

Background

Sharon Seaver¹ was in her 13th year when a nearly successful suicide attempt was thwarted by her hospital roommate's chance glance. This occurred during her readmission to a psychiatric facility from which she had been discharged two days earlier following a serious suicide attempt.

Sharon was adopted by the Seavers when she was a newborn. She attained developmental milestones within normal limits and her biological parents had no known history of substance abuse, alcoholism, or mental illness. Aside from chronic asthma controlled with Ventolin, Sharon was in good health. She reported that she had been sexually active since age 12 and denied any history of physical, sexual, or emotional abuse.

The Seavers divorced when Sharon was five years old, and she lived with her adoptive mother for six years. She then went to live with her adoptive father in New Jersey. According to Mrs. Seaver, Sharon had difficulty adjusting to the divorce.

According to Sharon, she and her father argued incessantly, especially about school attendance. She also did not get along with her stepmother. Previously an honor student, Sharon began failing courses in the 8th grade. She was placed on probation after the school charged her with possession of a weapon; court-ordered psychotherapy was also part of the probation condition. Sharon moved back to her adoptive's mother's home in New York when she was 13.

Psychiatric History

Sharon attempted suicide twice: one time by taking an overdose of Tylenol and the second by slashing her wrists. Although she was treated in general hospitals for these attempts, she was never admitted.

Sharon's first psychiatric hospitalization occurred after she moved back to her mother's home. After a fight with her friend, Sharon slashed her wrists which required a total of 12 sutures, stated she wanted to kill herself, and resisted arrest because she didn't want to be hospitalized. The precipitating factors to her admission included: failure at outpatient treatment, suicide attempt, unmanageable at home and school, and family conflict. Her provisional diagnosis was Depression NOS, R/O Bipolar Disorder, R/O Conduct Disorder.

During her ten-day stay, Sharon was treated with Depakote and Zoloft, and attended daily psychotherapy sessions. According to the treating physician, Sharon had the capacity to contract for safety—meaning she would seek help from her mother or someone else if she felt suicidal—therefore it was believed Sharon was ready for discharge. Sharon was discharged from the hospital on a Wednesday and was enrolled to begin the hospital's all-day outpatient program on Thursday.

The Second Admission

On that Thursday night, Sharon fought with her mother. Reportedly, Sharon "went berserk," threw chairs, broke a glass door, and verbalized that she wanted to kill her mother. After Sharon ran off, her mother called the police. The police found and restrained her, and she was transported by EMS to the hospital where she was readmitted at 4:00 a.m., Friday morning. According to the psychiatric exam, Sharon was agitated, anxious, and verbalized active suicidal ideation: "I can't use pot so I want to die," as well as feelings of hopelessness, worthlessness, and affective lability. Her Depakote was increased to 1500 mg daily and Zoloft was discontinued.

The Incident

The admitting physician initially ordered Close Observation (CO) (15 minute checks). This verbal order was given to the Charge Nurse who wrote it in Sharon's chart. After reviewing

¹ All names are pseudonyms.

Sharon's record in more detail, the admitting physician upgraded his CO order to Suicide Observation (SO) (always within eyesight). This written order was sent up to the unit with Sharon; however, the Charge Nurse for that shift never changed the supervision level in Sharon's chart. When a patient is on SO, specific steps are taken to assure a patient's safety; one of these steps is to take away the patient's shoelaces. As the change in supervision level was missed, this procedure was not implemented.

On Friday morning, around 11:15 a.m., Sharon was restrained, and during the course of the restraint the order for SO was discovered; however, hospital staff again failed to follow the appropriate procedure—once again, Sharon's shoelaces were not taken away from her.

On Saturday, Ms. Francis, the Charge Nurse, made assignments for the 8:00 a.m. - 4:00 p.m. shift. Patients can be designated into one of two tracks. Sharon was designated for Track II which offered specialized groups for patients with drug abuse/use histories. Ms. Francis handed Sharon's assignment sheet with the designation of SO clearly written on top of the page to Mr. Pointer, a Substance Abuse Counselor, with the expectation that he could maintain the observation level for Sharon while she was in his groups. As Sharon could not leave the unit because she was a newly admitted patient and on restrictions, it was expected that Mr. Pointer would turn over his SO responsibility to a Psychiatric Attendant (PA) on the unit if the group went off the unit. Although patients should always be within eyesight of the assigned staff, flow (or check) sheets for patients on SO were to be completed by staff every 15 minutes.

The Attempt

That Saturday Sharon slept until 10:30 a.m.; upon awakening she spent a half an hour in the day area, a half hour getting showered and dressed, and another half an hour at a community meeting. About noon, Mr. Pointer was off the unit. The 12:15 p.m. note by Mr. Arden, a PA who was doing a "head count," indicated that Sharon was lying on her bed with her eyes open. At approximately 12:20 p.m., Sharon's roommate entered the room and saw the closet door half open and Sharon's hair. She thought Sharon was packing her clothes until she saw the shoelaces by Sharon's throat and tied to a hanger. She tried to untie the laces but they were tied too tight, and she couldn't lift Sharon so she went to the nurse's station and informed the staff that Sharon was "trying to hang herself."

Ms. Francis, Mr. Arden, and another PA immediately went to Sharon's room. They found her in the closet with two shoelaces tied around her neck with one end of the shoelace tied to a plastic coat hanger hook. She was facing out from the closet with both feet flat on the floor, knees slightly bent, eyes closed. The shoelace was taut. Ms. Francis and Mr. Arden lifted Sharon to relieve the pressure, and a Code was called while they loosened the shoelace and lowered Sharon to the floor. At this time, Sharon responded to questions from the medical and other hospital staff who answered the Code; she was oriented to person, place, and events, and responsive to staff directions. Sharon was immediately transferred to a general hospital for evaluation. She was medically cleared and returned to the psychiatric facility.

Investigation Results

The facility's investigation revealed that no one person could be held solely accountable for the breakdown in supervision of Sharon while she was on Suicide Observation.

Mr. Pointer acknowledged that Ms. Francis handed him the assignment sheet and told him his assignment to which he replied, "fine, no problem;" however, he did not understand that the SO responsibility for Sharon was his, nor did he realize that he should turn over this responsibility when he and the group went off the unit. Mr. Pointer had just returned from extended sick leave; during his absence the hospital redefined the structure of units and duties of various disciplines; the role of a Substance Abuse Counselor, such as Mr. Pointer, took on additional responsibilities such as providing special levels of supervision. The Director of Nursing reported that he couldn't be sure whether Mr. Pointer had received inservice training regarding the requirements of this new role, the responsibilities associated with CO and SO assignments, or the procedure for getting assigned relief when he went off the unit.

The facility also found evidence that Mr. Arden was unclear about the procedures for SO; he did a 15-minute "room check" and documented the SO Flow Sheet; however, according to the hospital's policy Sharon should have been in his eyesight at all times.

There was also a breakdown in the review of staff's SO responsibilities by the Charge Nurse who monitored the Flow Sheets. Although Ms. Francis reviewed the flow sheets for timeliness of documentation, she did not look at *who* signed the flow sheets. The documentation on Sharon's flow sheet was made by several PAs over the shift; but Mr. Pointer's signature was not found on the flow sheet. Sharon's level of supervision required that she always be within eyesight; however, the flow sheets read like staff did 15-minute checks on her instead, which was not in strict adherence to the SO policy.

Additionally, procedures were not appropriately followed during Sharon's admission: the Charge Nurse failed to change the supervision level from CO to SO in Sharon's chart, and as a result her shoelaces were never taken from her. And even when the correct supervision level was clarified, the shoelaces still were not removed.

The Lessons Learned

Although Sharon did not sustain any injuries, she was placed at substantial risk of death because of a serious breakdown in procedure at the hospital. As a result of the investigation, the hospital instituted corrective actions, including debriefing the roommate who discovered Sharon, disciplinary activities (written counselling of the Charge Nurse), training for counselors on the additional job responsibilities including provision of CO and SO supervision, environmental changes (removed the hooks; shelves to be installed), and policy revisions which eliminated the old SO status and replaced it with a 1:1 designation (within arms reach) or close observation designation (15 minute checks).

However, the events leading up to Sharon's near-miss suicide attempt offer several lessons for other hospitals serving individuals with psychiatric disabilities:

- Do facility policies explicitly delineate the responsibilities that staff have when assigned patients who require a level of special observation status; and are these responsibilities stated in behaviorally explicit terminology readily understood by and communicated to all parties?
- Are staff adequately trained on the provisions of special supervision?
- Are all staff provided timely inservice training when facility policies and procedures are revised?
- Do facility policies provide a formalized system for relief of staff from their special observation responsibilities during breaks or when they are off the unit?
- Does the facility have a mechanism in place that assures the appropriate procedures have been followed when a person is admitted and whenever the patient's status is changed?
- And finally, has the facility taken steps in the prevention of hanging suicides, which are by far the most frequent form of inpatient suicides?² A large percentage of suicides take place in bathrooms or private and semi-private bedrooms. Has the facility taken steps to remove the potential "hanging hazards" such as showerheads, nonbreakaway bars in shower and toilet stalls, wardrobes, exposed overhead pipes, window latches, hooks, hinges, etc.?

Agency Self Assessment

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

² See the Commission's report *Preventing Inpatient Suicides*, May 1989.

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 Jeff Kerwin: What Would You Have Done?

*Reprinted from the Commission's Monograph,
Choice & Responsibility Legal and Ethical Dilemmas
in Services for Persons with Mental Disabilities*

Introduction

This is the story of Jeff Kerwin (a pseudonym), whose life and death—at age 37 due to complications from Prader-Willi syndrome—are testimony to the very real service delivery dilemma: when client rights and choices clash with professional responsibilities.¹

Prader-Willi syndrome (PWS) is a developmental disability afflicting between four to ten people out of every 100,000. A complex disorder with multiple physical, cognitive, and behavioral characteristics, PWS was identified as a clinical entity and a birth defect only in the late 1950s. Since then, genetic studies have linked PWS to anomalies in chromosome #15 in a majority of cases; in others, the disorder's etiology is less clear.

Among the key clinical characteristics of PWS are:

Jeff Kerwin's life and death are testimony to the very real dilemma: when client rights and choices clash with professional responsibilities.

□ Hyperphagia and Obesity

Although at birth infants with PWS have a poor sucking ability, difficulty swallowing, and little interest in feeding, within the first years of life food becomes their dominant, compelling interest. Young children, adolescents, and adults with PWS will consume any food in sight. Never feeling satiated, the person with PWS will continue to eat as long as food is available and, if left unchecked, will search for more: raiding cupboards, rummaging through garbage cans, and sometimes even stealing from stores or neighbors' houses. Uncontrolled, the person with PWS, even as a child, will become obese to the point that mobility is impaired and life jeopardized.

❑ Impaired Cognitive Ability

Almost all individuals with PWS (97%) have some degree of mental retardation, although some have been found with IQs as high as 100. Typically, IQs range between 20 and 90, and the average IQ is 65. Most individuals with PWS fall within the mild mental retardation/borderline intelligence strata.

❑ Physical Anomalies

In addition to uncontrollable hunger, obesity, and retarded mental development, people with PWS share other unique physical characteristics including

There is no cure for Prader-Willi syndrome. Treatment focuses on addressing its symptoms, chiefly the excessive weight gain. Absent interventions, the prognosis is bleak and promises early death from obesity-related problems.

hypotonia (poor muscle coordination and tone) which affects mobility and respiratory and skeletal systems; hypogonadism (underdeveloped or disordered primary and secondary sexual characteristics) which affects fertility, sexual identity, and self-esteem; and other physical anomalies including short stature, abnormally small hands and feet, unusual facial features, and a tendency to bruise easily, compounded by a propensity to pick at skin injuries—often leading to infections.

❑ Behavioral/Social Difficulties

Although described as generally having pleasant dispositions, persons with PWS are prone to episodes of emotional, violent outbursts and temper tantrums, as well as bouts of depression. Contributing factors include: frustration over inability to obtain food, social rejection by peers, and a sense of "needing to be in control," usually related to food intake. Episodes of manipulation, property destruction, stealing or foraging for food, and depression are mingled with periods of "naive friendliness, docility, and affability," as described in the literature.

There is no cure for Prader-Willi syndrome. Rather, treatment focuses on addressing its symptoms, chiefly the excessive weight gain and associated problems, through strict environmental and dietary controls and behavior modification. Absent these interventions, the prognosis for individuals with PWS is bleak and promises early death from obesity-related problems (diabetes, heart or kidney failure, etc.), or possibly poisoning (stemming from

food foraging activities), or infection (associated with poor circulation, skin-picking behavior, and reduced sensitivity to pain).²

The Early Years

Jeff Kerwin was born in 1957, one year after Prader-Willi was identified as a clinical syndrome by the Swiss physicians for whom it was named.

Clinical records are silent on many aspects of his early years; however, they revealed that he was the product of a full-term pregnancy and normal delivery, but as an infant had poor sucking reflexes and muscle tone. He was described as a "floppy baby" and had delayed developmental milestones. Soon after his birth, Jeff's parents divorced, and his mother eventually remarried.

Throughout his childhood and adolescence, Jeff lived with his mother and stepfather in upstate New York and attended special education programs. The records reviewed did not shed much light on Jeff's weight or eating habits during these years, or

when Prader-Willi syndrome was entertained as a possible diagnosis. It is documented, however, that Jeff tested in the borderline range of intelligence and was obese.

According to Jeff's mother, Jeff was not diagnosed as having Prader-Willi syndrome until the early 1980s when he was in his 20s. Until then, she knew he was "different" and had emotional, behavioral, and learning difficulties, but the cause was not clear.

Primary among his problems, according to his mother, was his uncontrollable eating and excessive weight. Less than 5 feet tall, Jeff's weight fluctuated between 200 to over 400 pounds. To control his eating, the family locked cupboards and chained the refrigerator shut. As Jeff would unscrew hinges or handles to gain access to food, or steal from neighbors' houses, someone had to be with him almost constantly, and it was nearly impossible to take him out to social functions or to visit relatives or friends. Mrs. Kerwin reported that neither she nor her husband had much of an out-of-home life as all of their energy was spent trying to limit Jeff's access to food, a constant struggle in which Jeff usually prevailed.

Following completion of his special education school program and receipt of his General Education Diploma, Jeff continued to live with his parents. For a brief period he attended a sheltered workshop, but dropped out and spent his days at home.

Jeff was diagnosed as having Prader-Willi when he was in his 20s. To control his eating, the family locked cupboards and chained the refrigerator shut.

Sometime after the diagnosis of PWS was made, Jeff was admitted to a nutritional rehabilitation program in Connecticut. The year was 1983, he was 26 years old and, at 4 feet 10 inches tall, weighed 390 pounds. The placement was short-lived, however, and Jeff was discharged due to his frequent emotional outbursts and tendency to victimize other residents—stealing their food and money (to buy food).

Upon discharge, Jeff entered a community residence for developmentally disabled persons near his family in upstate New York. However, he was soon discharged due to his tantrums and refusals to follow staff directions and the rules of the house. For several months, Jeff lived independently. According to family members, he did not care for himself properly and gained additional

At age 30 he was admitted to a community residence developed to serve individuals with PWS.

weight. During this period he also developed severe and recurrent leg ulcers, due to poor circulation. Treatment of the ulcers required inpatient care at a local hospital. Following discharge from the hospital, Jeff lived with his parents and received outpatient services from the local district

office of the State Office of Mental Retardation and Developmental Disabilities. The services, which consisted of counseling and family supports, were conducted in the home, as Jeff refused to leave the family residence for work, social, or recreational programs.

A Special Placement

By 1986, Jeff's family was unable to manage him at home, and at age 29 he was admitted to an eight-bed community residence developed by the Office of Mental Retardation and Developmental Disabilities to serve individuals with PWS. It was located more than 200 miles from his home.

The residence provided strict environmental controls to limit food access (including locked cupboards and refrigerator), as well as special nutritional and exercise regimens and behavior modification and counseling services. It was also the expectation that all residents would engage in, and be challenged and rewarded by, meaningful daytime activities. All aspects of daily life were highly controlled and monitored to ensure health—including smoking, which was one of Jeff's pleasures, but is strongly ill-advised for persons with PWS.

Entering the residence weighing over 400 pounds, over the next five years through environmental and behavior controls, diet, exercise, and counseling, Jeff lost approximately 250 pounds, coming within 30 pounds of his ideal body

weight (IBW) of 95–121 pounds. He also began attending a sheltered workshop where he earned over \$50 a week, when he was willing to work.

During this period, genetic testing revealed deficiencies in chromosome #15, confirming the PWS diagnosis, and intelligence testing resulted in a full-range IQ score of 71, indicating that Jeff was of borderline intelligence. Health-wise, Jeff suffered a number of the side effects of his obesity/PWS, including high blood pressure, congestive heart failure, and poor circulation. Excessive fat tissue and recurrent leg ulcers prompted several surgical interventions (liposuction and skin grafts).

According to his mother and residence staff, the years Jeff spent in this facility were among his healthiest—he tended to health issues, engaged in work activities and, for a period of time, kept his weight down to about 150 pounds. However, according to his mother and facility staff, he also developed a sense of what were his “individual rights” and an increased determination to exercise his views on this matter.

Admitted to the residence on a voluntary basis, in time, Jeff began to rebel against its regimented structure. He would elope from the program, only to be returned; sneak food into the residence; demand to be allowed to smoke; etc. While on visits to the family home on holidays, to which he could travel independently, Jeff would break from his special diet regimen and gain excessive amounts of weight, sometimes up to 20 pounds in a two-week period.

According to his mother and residence staff, the years Jeff spent in this facility were among his healthiest.

After more than five years in the residential program, Jeff demanded to be discharged. He was transferred to a developmental center. The purpose of the placement was to provide respite—it was hoped that Jeff would return to the PWS residence voluntarily.

The Placement Ends, October 1991

Eventually, in October 1991, at age 34 after more than five years in the residential program and increasing elopements and complaints about the home’s rigid rules, Jeff demanded to be discharged. He was transferred to the local state developmental center in whose catchment area the residence was located. The center is a several-hundred-bed institution serving a population

by and large far more disabled and lower functioning than Jeff. The purpose of the placement was to provide Jeff respite—a safe haven and a cooling-off period of several weeks—after which, it was planned, or rather hoped, that Jeff would return to the PWS residence voluntarily.

While in the center, however, Jeff stole food from other residents and engaged in property destruction, assaults, and self-injurious behavior. He disagreed with the plan to return to the PWS residence and, asserting his right not to be held in the center against his will, formally demanded his release/discharge. He stated that he wanted to live independently in his own apartment. Although Jeff was fairly high functioning—able to read and write on a third-grade level, travel independently, and manage money to some extent—clinicians were concerned that he had little insight or motivation to manage his PWS and related health care needs. It was felt that if he lived independently, he would not adhere to his special diet or care for his recurrent leg ulcers and infections, and thus his health would be severely compromised.

In October 1991, the facility applied to the Supreme Court for an order authorizing Jeff's involuntary retention and treatment at the center. Citing Jeff's diagnosis of Prader-Willi syndrome, his borderline intelligence, his history of gaining excessive weight resulting in compromised health while living independently, and his resistance to proper dietary and exercise regi-

Jeff agreed to a plan: placement in a supervised community residence, but not a Prader-Willi residence. He agreed to a voluntary transfer to a developmental center near his parents from which he could be placed in a community residence.

mens which would benefit him, as well as his resistance to medical attention for recurrent leg ulcers, the facility indicated that Jeff was at risk for a variety of medical complications and death. The facility posited that Jeff required care and treatment for his developmental disability and that his judgement was so impaired that he was unable to understand

the need for such care and, as a result, posed a substantial threat of physical harm to himself or others. The Court authorized Jeff's involuntary retention for a period of 60 days.

During the next two months, facility staff worked with Jeff to try to develop a viable treatment and placement plan. It was clear to staff that the developmental center was not the most appropriate placement for Jeff, given his abilities. Staff also noted that there was no compelling evidence that Jeff's condition posed an *immediate* danger warranting the restrictive setting and

services of the center, and that if a court hearing was held at the end of the 60-day involuntary retention period, the judge might order his immediate release. Staff appreciated, however, that once on his own, Jeff's overeating might eventually result in life-threatening health problems.

Jeff, on the other hand, was adamant that he would never return to the Prader-Willi residence, with all its restrictions and rules, asserting that he knew his rights and nobody could make him. He also protested (and broke) the rules of the developmental center, particularly those pertaining to smoking and eating. For example, upset with the "no smoking" plan staff developed for him, Jeff secured the assistance of a legal service which fashioned a compromise agreement that Jeff could smoke, but only five to eight cigarettes a day.

He would demand his personal allowance and spend it as he saw fit, sometimes purchasing and eating up to 15 candy bars at a time.

Toward the end of the two-month involuntary retention period, as staff were preparing an application for a one-year, court-ordered involuntary commitment, Jeff agreed to a plan: placement in a supervised community residence, but not a Prader-Willi residence. As he also wanted to live closer to his family, he agreed to a voluntary transfer to a developmental center near his parents from which he could be placed in a community residence, once a bed became available. His family was agreeable to the plan.

At the New Center, March 1992

Jeff arrived at the new developmental center, a several-hundred-bed facility in upstate New York, in late March 1992. At that time he was 34 years old and weighed 178 pounds.

From the time of arrival, Jeff tended to be isolative and manipulative, according to the center's records. He refused to follow a special diet designed to address his PWS. (The diet consisted of three regular daily meals totaling 1,000 calories, with several snacks in between consisting of salads and Jello.) Claiming, "It is my money, and I have a right to it," he would demand his personal allowance funds and spend as he saw fit, sometimes purchasing and eating up to 15 candy bars at a time. He also broke the facility's smoking rules, stole from others, and engaged in property destruction and self-abuse if staff attempted to set limits. At one point he opened one of the skin grafts on his leg with a nail clipper when he felt staff were infringing on his rights. (Initially, he refused to allow staff to tend to his ulcerous legs, but in time relented and even became proficient in caring for them himself.)

Although Jeff participated productively in a workshop where he earned money, he refused to cooperate with professional staff, even those responsible for conducting assessments. He refused to speak with psychologists, social workers, and the nutritionist.

As he refused to speak, attempts to conduct full-scale intelligence testing, last completed in 1986, were futile. On the basis of staff observations,

Almost two months after admission, Jeff had gained over 30 pounds and weighed 210 pounds.

however, an Adaptive Behavior Scale was performed.

This indicated that Jeff's daily living skills were on par with those of an adult, but that his socialization skills were the equivalent of a ten-year-old child, largely due to his poor coping abilities. His communication skills were about on the same level.

But his fine and gross motors skills were on par with those of a five-year-old child, largely due to physiological problems associated with his PWS.

After weeks of attempted assessments and observations, Jeff was assigned the diagnoses of borderline intelligence, Prader-Willi syndrome, conduct disorder, and passive-aggressive disorder. Although considered, it was not felt that he suffered from a psychotic disorder. Medically, he was diagnosed as having a number of problems associated with his PWS, including morbid obesity, chronic leg ulcers, circulatory problems, and a history of hypertension and congestive heart failure.

By mid-May 1992, almost two months after admission, Jeff had gained over 30 pounds and weighed 210 pounds. Consultants were called in on the case. It was their impression that the developmental center, given its size and population mix, was not the most appropriate environment to afford the degree of structure Jeff required, given his unique needs, and that he would best benefit from a smaller, highly structured community residence or a behaviorally oriented family care home. They also noted, however, that the center should target the most important behaviors which *must* (emphasis theirs) be controlled, such as Jeff's stealing, food scavenging and aggression, while he remained in the center.

The consultants recommended that a very highly structured behavior management plan be developed to begin to address the target behaviors and that a search for a small, but very structured, community-based program be initiated.

About two weeks after the consultants' report was received, Jeff eloped from the facility.

Discharge Planning, June 1992

Within three days Jeff was found and returned to the center, whereupon he demanded to be released.

Senior clinicians conducted assessments and conferred, concluding that Jeff was not in immediate danger. They also concluded that Jeff suffered no clinical condition which would warrant petitioning a court for his involuntary retention: while he was overweight and prone to ulcers, his medical condition, including blood pressure and ulcers, was stable; he suffered no infections; he was able to care for his skin condition; and, on interview, he indicated that he would "assume responsibility" for reasonable caloric intake.

Jeff was agreeable to staff's suggestions that he stay at the facility for a couple of days so that placement and discharge plans could be arranged. However, he resisted all suggestions of supervised community residences which, in staff's opinion, offered the structure needed for management of his PWS.

The only option Jeff would agree to, short of living independently, was a home for adults, which essentially offers room and board and a minimal degree of supervision (regulations require one staff person for every 40 residents).

On June 10, 1992, Jeff was released to a 375-bed adult home which he had visited and liked.

The discharge plan called for Jeff to live in the adult home temporarily, until he was willing to move to a more supervised setting. For his health needs, Jeff was to attend a family practice clinic of a local hospital. He was also to be referred to the State's Office of Vocational and Educational Services for Individuals with Disabilities (VESID) to be assessed and trained for vocational/daytime activities.

According to the plan, staff of the developmental center's outpatient services, including a case manager and a nurse, were to visit Jeff regularly to monitor his status and intervene or advocate for additional services when the need arose.

The discharge plan noted that these were not the most desirable or appropriate arrangements for Jeff, but the best ones possible given his resistance to other service options, including staying at the center until alternative arrangements could be made, and the absence of clinical conditions which would justify his involuntary retention.

*Jeff demanded to be released.
Senior clinicians conducted
assessments and conferred,
concluding that Jeff was not in
immediate danger.*

The plan also noted that Jeff's mother was consulted on the matter and reluctantly agreed to the discharge while citing concerns over his PWS and his inability to independently manage this condition.

Five months after Jeff's death, his mother told investigators that she cried and begged center staff not to release her son. She claimed facility staff advised

From the onset, Jeff's attempt at independent living was fraught with problems.

her that they had no legal recourse but to let him go, and counseled her on "rights and dignity" issues. She told investigators that she questioned, "What about his right to live? Where is the dignity in being allowed to eat impulsively, with no controls, to the

point of death?" But, she relented to the plan, she said, because, "They knew the law, they were the professionals...but they didn't know my son."

Freedom and Death, June 1992–August 1993

From the onset, Jeff's attempt at independent living and life in the community was fraught with problems.

He refused referrals to VESID, as he did not want to be associated with programs which served "the retarded." His relationship with the family practice clinic quickly ended after he was reportedly demanding, yet non-compliant. Depending on whom one spoke with, Jeff either "wore out his welcome at the clinic," due to his behaviors, or just plain refused to go to the clinic.

More significantly, Jeff's residential arrangement fell apart. Upon arrival at the adult home, he soon got into altercations and arguments with staff and fellow residents. He was ridiculed by the home's clientele over his appearance and taunted with questions like: "Are you a man or a woman?" He reportedly stole money from residents and, when he didn't get his way, threatened others with harm. When arguments escalated to the point of becoming physical, police were called. Within 60 days, the adult home management initiated eviction proceedings against Jeff, as his behaviors threatened the well-being of other residents and substantially interfered with the orderly operations of the facility.

Following eviction in August 1992, Jeff moved through a succession of placements in welfare hotels and one brief, five-day stay in a community residence. During this period, he was robbed, arrested for shoplifting candy and cigarettes, and neglectful of his personal hygiene. He was noted, by staff in the respite community residence, to be malodorous and spending his allowance on bags of junk food.

From the time of Jeff's discharge from the developmental center in June 1992, the case manager from the center maintained nearly daily contact with him. Many of the contacts were of a crisis nature: trying to mediate problems in the adult home; assisting Jeff secure new housing; resolving Jeff's legal problems; and helping Jeff secure entitlements or extra money when he was short of funds. But during the calm between storms, the case manager maintained just as frequent contact with Jeff: taking him to dinner or food shopping (to ensure, to some degree, he was eating a healthy diet); reminding him to bathe; socializing with him; and encouraging him to become involved in VESID services or other daytime activities, including volunteer work, in which Jeff expressed a fleeting interest. By early November, the case manager found an apartment for Jeff, so he would no longer have to live in a spartan hotel room. Together they furnished and decorated it, shopping for furniture, curtains, cleaning and cooking materials, etc.

Jeff appeared to be gaining weight, and periodically his leg ulcers were infected.

The nurse from the developmental center also visited Jeff regularly to monitor his health status. During visits by the nurse, or even to the doctor's office, Jeff refused to be weighed; the nurse, however, noted that he appeared to be gaining weight. She also noted that while grocery shopping, Jeff would buy pie and pudding, in addition to excessive amounts of meat. (It appears, based on the comments of others who visited Jeff and found empty pizza boxes and other food containers, that he also called for take-out deliveries.)

Periodically, the nurse would find that Jeff's leg ulcers were infected, draining purulent fluid. On these occasions, she would arrange for a visit to the doctor. Although Jeff would not comply with the physician's requests and advice concerning his weight, the nurse noted he would follow the physician's orders (topical antibiotics and fresh dressings) for the leg infections which, in time, would improve.

By December 1992, Jeff had begun to experience other problems. Due to his increased weight and ambulation problems, he had difficulty using the bathroom in his apartment. He needed a toilet raiser, grab bars to ensure safety getting in and out of the shower/tub area, and a hand-held shower head so that he could more thoroughly wash. He was also informed that the developmental center was planning to transfer his outpatient services to a not-for-profit agency in the area which would continue his case management services, a change that made Jeff uneasy. And, on occasion, he was lonely; he would call

the developmental center's Administrator on Duty, who in turn would call the case manager who would promptly visit Jeff.

Jeff's case manager and others from the developmental center worked on securing adaptive equipment for his bathroom. But they also encouraged him

He stated he was happy and that he would rather have one year of life in his apartment, than ten years in a residential program.

to return to the developmental center, or move to a community residence, or agree to admission to a rehabilitation center in Pennsylvania which specialized in the treatment of PWS. Jeff refused. He stated he was happy and that he would rather have one year of life in

his apartment, than ten years in a residential program. He even refused offers to return to the developmental center, even on a periodic basis, to use its facilities for showering, socializing, etc.

Over the next six months (January–June 1993), Jeff continued to gain weight. Although he refused to be weighed, staff saw an obvious increase in his size to the point where it was difficult to find and purchase clothes which fit; they also noted that while shopping, Jeff would load up on bread, nuts, and other ill-advised food items. He refused to listen to their suggestions on healthy choices. He experienced mood swings and periods of sadness and sleeping difficulties; but he rejected his physician's suggestion of trying the medication Prozac to treat his emotional difficulties, as well as his rigidity/compulsive eating. He also experienced periodic problems with his leg ulcers, which he would only sometimes allow nursing staff to treat. And he continued to reject suggestions that he move to a more supervised setting or seek admission to the PWS rehabilitation facility in Pennsylvania.

During this period, Jeff's case management services were transferred from the developmental center to the private developmental disabilities service agency. This occurred gradually over period of several months so

that Jeff could become accustomed to his new case managers; as developmental center staff started to reduce and eventually fade-out their visits, staff from the private agency began to visit Jeff and increase the frequency of their visits.

Jeff continued to gain weight; he had difficulty walking even 10 feet and was taken to the hospital on two successive days for shortness of breath. It was felt that his episodes of shortness of breath were associated with his morbid obesity.

The plan called for staff from the private agency to visit Jeff ten hours weekly to help him with nutritional issues, housekeeping, and attending medical appointments. As Jeff was having increased difficulty ambulating due to his weight, the plan called for purchasing a scooter so he could get around outside his apartment and go to stores. Due to budget constraints, however, the private agency never received funding for a full ten hours of weekly staff service or for the scooter. Nevertheless, the agency's case manager visited Jeff nearly every other day. Arrangements were made for a nurse from the county health department to periodically assess Jeff's legs and overall health status.

The new case manager recorded her concerns about Jeff's failure to maintain his diet, as well as his gaining weight and refusing to allow the nurse to conduct assessments.

By the end of June 1993, the case manager notified her supervisor of her concerns over Jeff's health. He had difficulty walking even 10 feet. At about the same time, Jeff was taken to the hospital on two successive days for shortness of breath. On the first day he refused to be examined by anyone. His private physician was called by the hospital and attempted to speak with Jeff in the emergency room by phone. Jeff refused to speak to him and left the hospital against medical advice.

On the second day, Jeff allowed an assessment: his vital signs were within normal limits, his lungs were clear, and his respiratory status was normal. It was

felt that his periodic episodes of shortness of breath were associated with his morbid obesity, and he was referred to his private physician.

In early July, the case manager and her supervisor met with Jeff. By this point, his weight (believed to be in excess of 400 pounds and possibly closer to 500) impaired his ability to do simple tasks around his house; he even had difficulty standing and walking in his apartment. He was so large that he could no longer get into the shower/tub area, and it was felt he needed a specially designed shower area into which he could be rolled on a chair. He could no longer use the toilet, but he refused to discuss how he was managing this need. (The agency initiated a bidding process for bathroom renovations.)

During the meeting, agency staff expressed their concerns over Jeff's life and safety. He rejected their suggestions of placement in a supervised

Staff expressed their concerns over Jeff's life and safety. He rejected their suggestions of placement in a supervised residence, but agreed to admission to a Prader-Willi syndrome rehabilitation program in Pennsylvania.

residence, but agreed to admission to a Prader-Willi syndrome rehabilitation program in Pennsylvania. By this time, according to some people who knew him, Jeff was afraid and knew his PWS was out of control. However, in the opinion of others, including Jeff's private community-based physician whom Jeff had allowed to treat his leg ulcers on occasion, but not the PWS-related issues, Jeff did not really understand the nature and consequences of his PWS.

Staff of the private agency promptly sent out an application to the Pennsylvania program and followed this up with letters to his private physician

On August 27, 1993, Jeff died in his sleep. Prader-Willi syndrome was identified as a contributing factor. Days later, his case manager received notice that Jeff's admission to the center in Pennsylvania had been approved.

seeking additional clinical information to facilitate admission and to Medicaid officials requesting permission for out-of-state treatment.

Staff also arranged for daily aide service in Jeff's apartment to assist in house-keeping tasks, etc. But Jeff, who was now essentially bed-

or chair-bound, refused to allow anyone (i.e., visiting nurses) to assess his physical condition. He also refused to see his doctor, although by August he was complaining about his leg ulcers and feeling worse with every passing day.

Anticipating that Jeff would be approved for admission to the Pennsylvania program, staff started to make arrangements for his transportation to the program. However, on the morning of August 27, 1993, Jeff died in his sleep. His death was attributed to congestive heart failure; Prader-Willi syndrome was identified as a contributing factor.

Several days later, Jeff's case manager received notice that Jeff's admission to the rehabilitation center in Pennsylvania had been approved.

Discussion

The universal reaction to Jeff's death among those who knew him well—including family, nurses, clinicians, and case managers—was profound sadness. But this was accompanied by anger on the part of some who rued the day Jeff was released from the protective, yet restrictive, environment of supervised living; and discontent on the part of others who, while believing they acted on Jeff's behalf by respecting, even facilitating, his wish to live independently, were uncomfortable with the outcome—his death.

All, many in tears during interviews, questioned whether things could have, or should have, been done differently. Even with the clarity of hindsight

which tragedy often brings, each wrestled with what should have tipped the balance in decision-making: clinical opinions of what would be in Jeff's best

Decisions which expose individuals to little or no risk of harm do not warrant rigorous scrutiny or vigorous intervention by service providers.

interest, or Jeff's preference. Each wrestled with the dilemma posed when professional responsibility and client choice clash.

Increasingly, providers are facing this dilemma as the service system evolves from a very

paternalistic mode—in which clients' choices and wishes played a back seat role to "professional wisdom" about what is in their best interest—to one in which service recipients are seen as equal partners in steering the course of service delivery and whose wishes and choices should be as valued as the wisdom and advice of professionals.

While there are no easy answers as to what to do when partners in the service compact disagree over which direction their shared venture should go, there are guideposts to aide professionals in difficult decision-making. They call for: assessing whether the choice being expressed by the consumer is consistent with what is known to be his or her stable or persistent values, preferences, and interests; and assessing the probability, severity, and duration of harm, if any, associated with the choice being expressed by the consumer.

Decisions which expose individuals to little or no risk of harm and are clearly consistent with the known values and interests of the individual, even if they are ill-advised choices (such as a person with Prader-Willi syndrome going off his or her diet once a month), do not warrant rigorous scrutiny or vigorous intervention by service providers. However, as the risk of harm associated with an individual's choices increases, in terms of its probability, severity, or duration, or as it becomes less clear whether a choice expressed is consistent with the individual's values or best interests, the need for careful professional scrutiny and intervention likewise increases.

As the risk of harm increases, or as it becomes less clear whether a choice expressed is consistent with the individual's values or best interests, the need for careful professional scrutiny and intervention likewise increases.

Jeff consistently and clearly expressed his wishes; some—such as not wanting to be associated with "retarded people"—posed little danger or risk

and were not counter to his best interests. Others, such as his wanting to smoke, did not pose an imminent risk of harm. Yet others, chiefly his desire to live without constraints over his food intake, posed a high probability of serious harm which, left unchecked, would also pose imminent harm.

Jeff's legacy is a challenge to all service providers to reflect upon his life—his disabilities, his abilities and wishes, the services provided, and the decisions made—in

order that they are better prepared to respond to a conflict for which there are no easy answers: when clients' rights and choices clash with professional responsibilities.

- Jeff's diagnosis of Prader-Willi syndrome carried with it an early death sentence, unless his eating could be controlled by external parties. His history confirmed he was unable to independently control his food intake, and consequently he gained excessive amounts of weight and suffered health-related problems prior to admission to a facility with a controlled environment in 1986. Should he have been allowed to leave a controlled environment and live independently? Should staff have made more vigorous efforts to use involuntary commitment to keep him in a developmental center? What other alternatives did they have?
- His diagnosis of Prader-Willi syndrome was also accompanied with limited cognitive abilities, impaired mobility, and stunted emotional,

social, and physical development.

Should he have been allowed to live independently? Should his opinions and choices have been given the deference that they were?

Although developmentally disabled, Jeff, with an IQ of 71, was not "technically" mentally retarded. But was he, based on his clinical condition and history, suffering from a developmental disability about which he lacked

an understanding of the need for treatment? Should his opinions and choices have been given the deference that they were?

- During an eight-month period, between October 1991 and June 1992, two state developmental centers arrived at two different decisions about Jeff's clinical capacity to consent to treatment. The first center believed he lacked the ability to understand his need for treatment and

Jeff's diagnosis of Prader-Willi syndrome carried with it an early death sentence.

secured a court order for involuntary care when Jeff demanded to be discharged; the second center, confronted with the same clinical picture/information and Jeff's demands for release, discharged him. Should a court-ordered retention have been attempted?

- Were the discharge and aftercare plans for Jeff appropriate once he left the developmental center, was evicted from an adult home, and eventually settled into his own apartment? Should his noncompliance with plans to maintain his health while in the community—such as weight monitoring, compliance with dietary and medical regimens, etc.—have triggered additional action, including involuntary retention and treatment?
- When Jeff left the developmental center in June 1992, his health was relatively stable. Although overweight, his hypertension was under control; his skin condition was good; he had no infections, and he demonstrated an ability to tend to recurrent ulcers; and he asserted he would assume responsibility for reasonable caloric intake. Over the next 14 months, Jeff's weight more than doubled, his ulcers worsened and were periodically infected, he had difficulty walking even 10 feet, suffered respiratory difficulties, became bed- or chair-bound as he could not walk, and eventually died. Clearly, he left the developmental center in relatively good health, claiming he could care for himself; but in the ensuing months, his health declined to a life-threatening degree, illustrating his inability to properly care for himself. Should staff have intervened to ensure he received the services he required, even on an involuntary basis? At what point? When should concerns over his rights and choices have been overridden by concerns for his life and health? Who should have been involved in making this determination?
- Jeff, despite having Prader-Willi syndrome, associated health problems and limited cognitive abilities, wanted his freedom. He did not want to be associated with "retarded" people. He did not want his refrigerator locked, and cigarettes counted, or be denied the opportunity to go to a grocery store to buy what he wished. He did not want people inspecting his body or inquiring about his weight, which he

He wanted the opportunity of at least one year of living in freedom over the alternative of continued incarceration. Were the agencies which facilitated this wish assisting or harming Jeff?

already knew was too much, different, and embarrassing. After seven years in the controlled environments of developmental centers or community residences, he did not want to be associated with programs which made those demands or monitored his compliance. He wanted the opportunity of at least one year of living in freedom over the alternative of continued incarceration. Were the agencies which facilitated this wish assisting or harming Jeff?

- What would you have done?

Endnotes

1. Jeff Kerwin is a pseudonym for an individual whose August 1993 death was brought to the Commission's attention by one of the service agencies with which he had been affiliated. This case study was developed based on a review of Mr. Kerwin's residential and outpatient records and interviews with his mother and staff of agencies which provided him care.
2. See Cassidy, S. B. (1987). Prader-Willi syndrome: Characteristics, management, and etiology. *Alabama Journal of Medical Sciences*, 24(2), 169-175; Mitchell, L. (1980). *An overview of the Prader-Willi syndrome* (rev. ed.). Edina, MN: Prader-Willi syndrome Association; Welfare Research, Incorporated. (1984). *An introduction to neuroloical impairments in New York State*. Albany, NY: Author.

