In the Matter of Jacob Gordon:
Facing the Challenge of Supporting Individuals With Serious Mental Illness in the Community

A Report

by the
New York State Commission on Quality of Care
for the Mentally Disabled

and the
Mental Hygiene Medical Review Board

August 1995

In the Matter of Jacob Gordon: Facing the Challenge of Supporting Individuals With Serious Mental Illness in the Community

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NYS COMMISSION
ON QUALITY OF CARE
FOR THE MENTALLY DISABLED

Preface

*In the Matter of Jacob Gordon** presents the story of a young man's life and death at age 35 from Neuroleptic Malignant Syndrome, a rare and sometimes fatal reaction to psychotropic medication. It is a chronicle of his attempts to live his life as he saw fit, pursuing his dreams of a college degree and independence, and the attempts of his family and mental health service providers to assist him in these endeavors, while still assuring he received the services and treatment necessitated by his mental illness. It is also an account of how reliance upon a multiplicity of providers of community services, coupled with inadequate communication between them and a patient's resistance to their recommendations for treatment, can lead to a tragic outcome despite their substantial efforts.

Mr. Gordon was a gifted man, both intellectually and artistically. In his high school years, however, he began evidencing signs of emotional difficulties; he was subsequently diagnosed as having schizoaffective disorder.

During most of his adult life, Mr. Gordon suffered persistent symptoms of his illness—delusions, obsessive compulsive behaviors, social isolation and inattention to basic self-care needs. Exacerbations of paranoid delusions and/or suicide attempts or gestures precipitated several hospitalizations lasting from a few weeks to three or more months in duration. And over the years, Mr. Gordon was tried on a variety of antipsychotic medications, most of which caused adverse reactions and were ultimately discontinued. He was eventually started on Clozaril, a relatively new psychotropic medication. The medication had extraordinarily good effect, but Mr. Gordon demanded that the dosage level be lowered, and his symptoms returned.

Like most people, Mr. Gordon did not view himself in terms of his illness. He had his own vision and goals: he wanted to attend college, associate with, as he put it, healthy people, nurture his artistic talents, and live on his own. And like many individuals with serious mental illness, he was put off by things which tended to identify or label him as being mentally ill: he disliked taking medications, having to attend programs geared exclusively to mentally ill people, living with other mentally disabled adults, and keeping appointments with psychiatrists, therapists and case managers. (Report pp 4–9.)

A generation ago, a man like Jacob Gordon would have spent his years confined to a state institution which, at the cost of his privacy, liberties and the dreams he cherished, would have been responsible for providing food, clothing, shelter, medical and mental health care and the supervision he required, all under one roof.

Deinstitutionalization efforts and community-based mental health service developments over the past several decades offered Mr. Gordon an alternative, but also fragmented the responsibility for meeting his multiple needs.

Rather than idling his days in an institution, Mr. Gordon was able to live in the community of Manhattan, attend college, secure his degree in literature and pursue his artistic endeavors. This was possible largely through the support of his family and a network of professional caretakers who provided him a supportive living situation, intensive case management services, medication therapy and monitoring services, and opportunities for rehabilitation services. In his last three years, more than $140,000 in medicaid funds alone were expended on Mr. Gordon's behalf and at least ten service providers were involved in his care.

But while some of Mr. Gordon's dreams were fulfilled, other basic needs went unattended. He lived in filth and neglected his basic hygiene needs. Health problems were ignored as were critical family dynamic

* A pseudonym

and other treatment issues. Often he did not receive his medications as prescribed and when he went into a medication–related crisis, he did not receive timely emergency care and subsequently died. (Report pp 9–17.)

To a certain extent, the conditions Mr. Gordon endured in the quest of his dreams were the result of his own strong resistance to accepting his mental illness and the advice of his care providers concerning his need for treatment and supervision. (Report pp 18–19.) To a considerable extent, however, the sheer number of providers involved in his life and their poor communication and coordination with each other also played a role. While each provider saw a dimension of Mr. Gordon's life, no one knew the totality of his needs or assumed responsibility for addressing them. Thus, health problems known by one party, were not addressed by others; medication–compliance problems known by residential staff were believed to be largely nonexistent by Mr. Gordon's psychiatrist; while day program staff had not seen Mr. Gordon in weeks or months, his intensive case manager believed he was attending program fairly regularly; and when his landlord found Mr. Gordon in crisis the day before his death, he didn't know how to contact his primary service providers. (Report pp.19–20.)

With the dramatic reduction in state psychiatric center beds over the last several decades, there are thousands of individuals with serious mental illness living in the community relying on the support of multiple service providers. Most, like Mr Gordon, are attempting to control the course and direction of their lives. But many, like Mr. Gordon, disagree, to varying degrees, with the advice and recommendations of providers on how to manage their lives while coping with their illness. Ensuring that these individuals receive the care they require is a formidable challenge, and the risk of failure escalates as the degree of disagreement and the number of service providers involved in an individual's life increase.

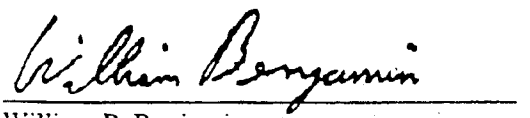
In this report, the Commission offers recommendations on how facilities could revise and revamp their policies and practices to better manage and reduce this risk of failure through enhanced service planning and interagency coordination. (Report pp. 21–22.)

The Office of Mental Health, which reviewed a draft version of the report, concurred with the Commission's recommendations and agreed to disseminate the report to all state–operated or licensed programs to serve as a teaching tool. The agencies which served Mr. Gordon were also requested to comment on the draft report. They voiced substantial concurrence with the Commission's findings. Community Access' response presents a consumer empowerment perspective on many of the issues raised in the report and is appended to the report for the reader's consideration, along with the responses of the OMH and the other agencies.

The findings, conclusions and recommendations contained in this report represent the unanimous opinions of the members of the Commission.

Clarence J. Sundram
Chairman

Elizabeth W. Stack
Commissioner



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Introduction

On May 28, 1994, Jacob Gordon[1] was found unresponsive on the hallway floor outside his apartment. The superintendent of the building who discovered him called 911 and Mr. Gordon was transported to Beth Israel Medical Center.

Mr. Gordon was admitted to the hospital in a coma with liver and renal failure, dehydration, an extremely elevated glucose level, and a fever of 102°, which climbed to more than 107°. Over the next nearly 24 hours, Mr. Gordon was treated for the possibilities of infection, poisoning, diabetes, and Neuroleptic Malignant Syndrome (NMS).[2]

Mr. Gordon died shortly after noon on May 29 with his family at his bedside.

However, his condition deteriorated and Mr. Gordon died shortly after noon on May 29 with his family at his bedside.

Mr. Gordon's sudden illness and death shocked his family, with whom he visited the day before being found in a coma, and staff of mental health agencies which provided him residential and outpatient care. At 35 years of age, he was somewhat overweight and had a history of hypertension, but had no other known medical problems which would have foreshadowed the events of May 28 and 29. Mr. Gordon's psychotropic medications, however, had been changed several days prior to his death; and his family requested an investigation into his care and the circumstances surrounding his death which, upon autopsy, was attributed to NMS.

His family requested an investigation into his care and the circumstances surrounding his death which, upon autopsy, was attributed to NMS.

In conducting the investigation, the Commission and its Mental Hygiene Medical Review Board reviewed the records of a private psychiatrist who treated Mr. Gordon, and records from the following agencies:

- Community Access, which provided Mr. Gordon residential and other services;
- The Visiting Nurse Service, which provided Mr. Gordon intensive case management services;
- Postgraduate Center for Mental Health, with which Mr. Gordon was affiliated for day treatment services;

[1] The names of all individuals in this report are pseudonyms.

[2] Neuroleptic Malignant Syndrome (NMS) is a rare but extremely dangerous reaction to neuroleptic medications seen in two-tenths of one percent of individuals treated with neuroleptics. The mortality rate of untreated NMS is approximately 30 percent. Key features of the syndrome include sudden high fever, high or unstable blood pressure, muscle rigidity, delirium, racing heart and sometimes labored breathing. Treatment includes discontinuing neuroleptic medications and instituting cooling and fever management measures and intravenous fluids. Dantrolene, to prevent muscle contractions, and Bromocriptine, to reverse the effects of the antipsychotic agent, are also often administered.

- Columbia Presbyterian Medical Center and St. Luke's–Roosevelt Hospital Center, where Mr. Gordon had received inpatient and outpatient psychiatric services in the past;
- Beth Israel Medical Center, where Mr. Gordon expired; and
- The New York City Medical Examiner's Office, which conducted the autopsy.

Commission staff interviewed Mr. Gordon's parents, his private psychiatrist, as well as more than 30 individuals from the above-referenced agencies who directly or indirectly provided Mr. Gordon services. These included case managers, residential staff who monitored medication and other issues, primary therapists, psychiatrists, and nurses and physicians who tended to Mr. Gordon in his final hours. The superintendent of Mr. Gordon's building and neighbors were also interviewed.

According to records, Mr. Gordon's psychiatric difficulties began in his high school years.

Findings

The Early Years

Mr. Gordon was born and raised in New York City. The elder of two siblings, Mr. Gordon appears to have had a normal childhood. Bright, with a reported IQ of 163, and healthy, Mr. Gordon excelled in school, as well as in sports. He was also a gifted musician.

According to records of his clinical history, Mr. Gordon's psychiatric difficulties began in his high school years. Reportedly disappointed that his band had not received a recording contract, Mr. Gordon became depressed and socially isolated. He also began to believe that he was unattractive and had a feminine or "babyish" facial appearance.

In 1979, following high school, Mr. Gordon moved to Boston to study music in college. Within the first year, however, he dropped out. For the next six years, Mr. Gordon lived in Boston and received financial support from his parents. During this period, he reportedly underwent several procedures to transplant hair to his beard area to give him a more manly appearance. He also attempted suicide on at least one occasion by ingesting over–the–counter medications and was hospitalized for psychiatric care at least twice, according to his parents. While in Boston, Mr. Gordon was followed by a private therapist.

Mr. Gordon was diagnosed as having schizoaffective disorder. In the 1980's he had several brief psychiatric hospitalizations.

During his last hospitalization in the Boston area, Mr. Gordon's parents arranged for his return to New York City and admission to St. Luke's–Roosevelt Hospital Center. This occurred on December 18, 1986. During his 11–day hospitalization at St. Luke's–Roosevelt Hospital Center, Mr. Gordon was diagnosed as having schizoaffective disorder. He was treated with Haldol 40 mg. daily with good results.

Following his discharge in late 1986, Mr. Gordon attended one of St. Luke's–Roosevelt Hospital Center's outpatient clinics on a fairly regular basis. Over the next three years, he was plagued by continuing delusions of people following him or not liking him because of the way

he looked or because of his "opinions on Freud's theories." He also periodically experienced bouts of depression and suicidal ideation.

Despite the persistence of delusions and episodes of depression, Mr. Gordon was able to work part-time in a clerical capacity. He also returned to college part-time, majoring in literature.

During this period, he was candid about his dislike of psychotropic medications, his irregularity in taking them, and his desire to take lower doses. In an effort to address his continuing symptomatology, at various times Lithium, Stelazine, Trilafon, Sinequan and Doxepin were tried.

Despite the persistence of delusions and episodes of depression. Mr. Gordon was able to work part–time in a clerical capacity. He also returned to college part–time, majoring in literature, and reportedly did very well.

Initially upon return to New York City in 1986, Mr. Gordon lived with his parents. However, he moved to a hotel because, as he reported to clinicians, he frequently argued with his parents. He was supported financially by his parents whom he visited regularly. He eventually moved to his grandmother's apartment in the same building as his parents.

In January 1990, Mr. Gordon required hospitalization after he stopped attending his clinic, ceased taking his medications and became increasingly delusional. During the nearly six weeks he spent at St. Luke's–Roosevelt Hospital Center, Mr. Gordon was started on Lithium and Moban, to which he responded somewhat. In February 1990, he was discharged to his grandmother's apartment, but became noncompliant with medications and aftercare plans. He was quickly readmitted to St. Luke's–Roosevelt Hospital Center in March 1990 following a suicide attempt in which he slashed his wrist during an acute psychotic episode.

Mr. Gordon was hospitalized twice in 1990 and, given his adverse reactions to many psychotropic medications, it was decided that he should be placed, as a trial, on Clozaril, a relatively new neuroleptic medication.

Mr. Gordon remained an inpatient at St. Luke's–Roosevelt Hospital Center for four months. He was initially restarted on Lithium and Moban. As he continued to be acutely psychotic, pacing the floors, humming to himself and putting his fingers in his ears to block out his auditory hallucinations, his Moban was increased to 80 mg. daily (adults may be prescribed up to 225 mg. daily), but he developed severe akathisia.[3] A review of his treatment history, which included the use of multiple antipsychotic medications over time, indicated that Mr. Gordon tended to develop akathisia at low doses of high–potency neuroleptics and severe sedation on low–potency neuroleptics. Therefore, it was decided that Mr. Gordon should be placed, as a trial, on Clozaril, a relatively new neuroleptic with fewer side effects than older–generation antipsychotic agents.

The Lithium and Moban were discontinued and Mr. Gordon was placed on a dose of Clozaril 25 mg. daily. The initial response was one of severe sedation and confusion. However, these symptoms dissipated as the Clozaril dose was titrated upward to 350 mg. daily.

At this level, however, Mr. Gordon developed a fever of 102° with sweats and chills. Liver function test results, as well as white blood cell counts, were slightly elevated. Workups for infection were negative and

[3] A condition of motor restlessness, ranging from a feeling of inner disquiet to an inability to sit or lie quietly or to sleep.

in a few days the fever resolved and elevated blood levels returned to normal. It was believed these transitory abnormalities were therapeutic-drug related.

Mr. Gordon's Clozaril was increased to 400 mg. daily, his mental status improved greatly, with a remission of his psychotic symptomatology.

Mr. Gordon's Clozaril was increased to 400 mg. daily, his mental status improved greatly, with a remission of his psychotic symptomatology, and discharge planning was initiated.

It was determined that it would be inappropriate for Mr. Gordon to return to his grandmother's apartment; so it was arranged that he would live in a community residence sponsored by the Richmond Fellowship. For continuing clinical care as an outpatient, it was planned that Mr. Gordon would attend St. Luke's–Roosevelt Hospital Center's Partial Hospitalization Program (PHP)—a Monday through Friday, 9 a.m. to 4 p.m. program offering medication management services, individual and group therapy and socialization opportunities.

Mr. Gordon was also linked with an intensive case manager (ICM) from the Visiting Nurse Service who would monitor his placement in the community and compliance with various services, including attending the PHP, receiving weekly blood tests required when one is taking Clozaril,[4] and attending to his medical needs, i.e., mild hypertension.

Community Placement

Mr. Gordon was discharged from St. Luke's–Roosevelt Hospital Center to his new community residence in late July 1990. His compliance with elements of his aftercare plan over the next year can best be described as problematic.

Deemed ready for discharge, it was planned that Mr. Gordon would live in a community residence with an array of support services. Soon after discharge, the plan unraveled.

Almost immediately after moving into the residence, Mr. Gordon expressed his dissatisfaction over living in a group home setting. He disliked the home's rules about doing chores and attending resident group meetings; he also disliked having a roommate. He tended to not socialize with the other residents and was out of the house every chance he had, with no one knowing his whereabouts. He confided to his ICM that he wanted to live on his own in an apartment or a single room occupancy hotel. The ICM persistently encouraged Mr. Gordon to remain in the residence as it was his belief that Mr. Gordon needed some level of daily supervision. The ICM, however, often had difficulty meeting with Mr. Gordon as he would leave the residence before the ICM arrived for their scheduled appointments.

Although he initially attended the PHP program with some regularity following discharge from the hospital, in time Mr. Gordon began missing his daily sessions. In defense of his irregular attendance, Mr. Gordon cited the demands of college which he began attending part-time

[4] More than other neuroleptics, Clozaril carries a risk of agranulocytosis, a marked reduction of granulocytes, leading to infections and even death. Thus, patients on Clozaril must undergo weekly white blood cell (WBC) counts. Clozaril therapy must be interrupted if the total WBC falls below 3.0/cu.mm. and the patient must be closely monitored. If the WBC falls below 2.0/cu.mm., Clozaril must be discontinued and the patient should never be restarted on the medication.

to complete his degree in English literature. He also reported his dislike of group therapy and his preference to be around, as he put it, "healthy people."

Mr. Gordon advised his clinic psychiatrist that he would no longer take Clozaril at his regular dose of 400 mg. daily; he would agree only to 200 mg. daily.

Due to his noncompliance with the PHP's daily attendance requirements, Mr. Gordon was terminated from the program after several months and enrolled in one of St. Luke's–Roosevelt's clinic programs which he attended on a weekly or biweekly basis.

For the most part, Mr. Gordon was compliant with his need to undergo weekly blood tests associated with Clozaril therapy. On one occasion, in early 1991, blood test results indicated a drop in his WBC count, which was still within normal limits, and elevated liver function tests, which subsequently resolved. Following this, Mr. Gordon advised his clinic psychiatrist that he would no longer take Clozaril at his regular dose of 400 mg. daily; he would agree only to 200 mg. daily.

The psychiatrist cautioned Mr. Gordon that the reduction in medication may precipitate a return of psychotic symptoms. Mr. Gordon's ICM also urged him to remain on the 400 mg. level. Mr. Gordon, however, refused. He also refused to sign consent forms to release any physical health–related data from his private physician to the Visiting Nurse Service ICM.

Following the reduction in medications, Mr. Gordon gradually evidenced signs of decompensation: he became more evasive, was noted to be talking to himself, missed scheduled appointments more frequently and increasingly neglected basic grooming and hygiene needs, with which he had had problems historically. The ICM and others spoke with Mr. Gordon about their observations, but he denied he was decompensating and refused any increase in medications.

The psychiatrist cautioned Mr. Gordon that the reduction in medication may precipitate a return of psychotic symptoms. Mr. Gordon's ICM also urged him to remain on the 400 mg. level. Mr. Gordon, however, refused.

During his year at the Richmond Fellowship community residence, Mr. Gordon complained to his ICM about his mother's overinvolvement in his affairs; he wanted to be more independent. This created some tension for service providers. For example, on one occasion, Mrs. Gordon informed the clinic psychiatrist that she wanted her son to see a private psychiatrist for a consultation; she asked the clinic psychiatrist to contact the consulting psychiatrist and provide him with an overview of Mr. Gordon's history. But when the clinic psychiatrist spoke with Mr. Gordon about the matter, he refused to allow the clinic psychiatrist to speak with the consultant.

On another occasion, Mrs. Gordon called her son's ICM to report that her son had missed a doctor's appointment, that he needed to be seen, and that he was currently at his grandmother's home. The ICM immediately went to the grandmother's apartment to remind Mr. Gordon of the appointment. However, Mr. Gordon became upset with the ICM for visiting him at his grandmother's home, saying "it's not fair for you to come here." Mr. Gordon further explained that indeed he had missed an appointment, but it was one that his mother had set up and he never agreed to go.

Mrs. Gordon explained her actions by citing concerns over her son's decompensation; despite the array of service providers from different

agencies involved in his life, she was afraid he was falling through the cracks. The ICM assumed the role of speaking regularly with the service providers and providing Mrs. Gordon regular updates on her son's status.

Decompensation and Hospitalization

In July 1991, Mr. Gordon abruptly left the Richmond Fellowship residence and moved into a hotel. Despite the urging of his ICM, Mr. Gordon refused to return to the residence. Increasingly, he began missing appointments for blood work and sessions with his clinic psychiatrist, even though his ICM contacted him nearly daily to encourage him to go, to remind him of appointment times, to inquire if he went, and to reschedule appointments if he didn't. His functioning level worsened and at one point he visited a surgeon and had hair transplanted from his scalp to his beard.

In 1991, Mr. Gordon abruptly left the Richmond Fellowship residence and moved into a hotel. His functioning level worsened.

By September 1991 Mr. Gordon was extremely paranoid and spent most of his time wandering in a nearby park. Consideration was given to involuntarily committing him for inpatient psychiatric care; however, his family was worried that this would further traumatize him. It was agreed that attempts to convince him to seek hospitalization voluntarily should be made. Through his family's intervention, Mr. Gordon presented at Columbia Presbyterian Hospital on September 12, 1991 and was admitted.

Upon admission to Columbia Presbyterian Hospital, Mr. Gordon was extremely poorly groomed, his mood was depressed and affect was flat. He denied auditory and visual hallucinations, but appeared to be responding to internal stimuli. He expressed delusions of people not liking him because of his feminine facial appearance. His father also reported that he had been engaging in ritualistic, or compulsive behavior: turning the television on and off, spontaneously singing whenever he passed a telephone, etc.

Through his family's intervention, Mr. Gordon presented at Columbia Presbyterian Hospital and was admitted.

Given his medication history, he was restarted on Clozaril, which he had evidently stopped taking or significantly reduced, and the Clozaril was increased to 350 mg. daily. At this dosage level his liver enzymes became elevated: SGOT >100 (normal range: 1 to 50) and SGPT >300 (normal range: 1 to 55). A medical representative of Sandoz, the pharmaceutical corporation which manufactures Clozaril, was contacted by Columbia Presbyterian staff. According to the records, the representative reported that elevated liver enzymes are seen in one percent of Clozaril patients, most commonly in patients on low doses. He recommended increasing the Clozaril dose to 400 mg. daily and predicted that at that level the abnormalities would resolve.

Citing increased daytime somnolence, however, Mr. Gordon refused to allow his Clozaril regimen to be increased above the 350 mg. level, even after being informed of the elevated liver function test results and the advisability of a slightly higher dose. Mr. Gordon was also prescribed Orap 6 mg. daily, but developed akathisia. Therefore, the Orap was replaced by Trilafon 2 mg., another antipsychotic.

During his approximately 12-week stay at Columbia Presbyterian Hospital, Mr. Gordon's mood improved slowly and he began to socialize with fellow patients. However, he engaged only minimally in the unit's structured activities/groups and persisted in his belief that people didn't like him because of his appearance, and that this was the reason for his social isolation.

When Mr. Gordon was ready for discharge, it was planned that he would live in one of Community Access' supportive apartments.

During this hospitalization, Mr. Gordon's family and Visiting Nurse Service ICM worked on securing him housing, as he had terminated his relationship with Richmond Fellowship and everyone agreed that when discharge–ready Mr. Gordon would require some level of supervised housing. Mr. Gordon was accepted by Community Access, a voluntary agency which operated community residences with 24 hour–a–day supervision, supportive residences where staff visit clients several times weekly, and intensive–supportive residences which staff visit daily to monitor clients. Community Access also operated a psychosocial rehabilitation program, Club Access.

When Mr. Gordon was ready for discharge, it was planned that he would live in one of Community Access' supportive apartments, attend one of Columbia Presbyterian Hospital's outpatient psychiatric clinics for therapy and medications, visit a medical clinic for the monitoring of his elevated liver enzymes, resume his college studies part–time, and attend Club Access. His strengths were viewed as his intelligence, articulateness, ability to self–advocate, noninvolvement in substance or alcohol abuse, and willingness to engage in school/leisure-time activities. His limitations, according to records, were his poor self–care/daily-living skills, social isolation, and inconsistent medication compliance. The plan at the time of discharge called for Community Access to provide housing and monitor his daily–living and socialization needs. Through weekly visits, the Visiting Nurse Service ICM was to monitor Mr. Gordon's mental status, adjustment to community living and linkage to services.

From the time of placement with Community Access until his death, Mr. Gordon's life was marked by significant noncompliance with treatment plans and fluctuations in his mental status and functional abilities.

Mr. Gordon was discharged to a Community Access supportive apartment in lower Manhattan on December 16, 1991.

Life With Community Access

From the time of placement with Community Access until his death, Mr. Gordon's life was marked by significant noncompliance with treatment plans and fluctuations in his mental status and functional abilities. During this period, however, he pursued and attained his college degree, enjoyed community social events with his family, and showcased his musical compositions and art work for staff associated with his care.

Within months of arrival at his new residence, Mr. Gordon's psychiatrist left Columbia Presbyterian Hospital and, through his mother's intervention, he was linked with a private psychiatrist for medication management. He was also enrolled in a day program operated by the Postgraduate Center for Mental Health. However, Mr. Gordon frequently missed or arrived late for sessions with his private psychiatrist and at

the Postgraduate Center. He often missed appointments for the required weekly blood tests associated with Clozaril therapy. He also claimed that socialization programs available at Club Access were "below" his level, as such he was reluctant to attend.

Mr. Gordon complained about the number of care providers involved in his life: a private psychiatrist for medications, individual and group therapists from the Postgraduate Center, a case manager from Community Access and an ICM from the Visiting Nurse Service.

Case managers from Community Access, who visited Mr. Gordon several times weekly, as well as his ICM from the Visiting Nurse Service who visited at least weekly, would remind him of his appointments (and the importance of such), ask him if he attended them, and quickly reschedule appointments (particularly appointments for blood work monitoring) if he failed to keep them. Case managers offered to escort Mr. Gordon to his appointments or buy him an alarm clock or calendar so he could keep track of his appointments and the time, but he refused.

Mr. Gordon also complained about the number of care providers involved in his life: a private psychiatrist for medications, individual and group therapists from the Postgraduate Center, a case manager from Community Access and an ICM from the Visiting Nurse Service.

As there were concerns over Mr. Gordon's compliance with his daily medication regime of Clozaril 350 mg. and Trilafon 2 mg., Community Access arranged that the medications be stored at one of its 24 hour–a–day supervised residences and that Mr. Gordon report to that residence at appointed times to ingest his medications under staff's supervision. The supervised residence was located within several blocks of his supportive apartment. However, Mr. Gordon often would not report for medications, or arrive at the residence after "medication hours." (On those occasions when he arrived late, he was reportedly given his medications.)

When staff did visit Mr. Gordon in his apartment, the place was frequently filthy with overflowing garbage, dirty dishes piled in the sink, food containers left out, and roaches or mice. His personal hygiene was also sorely neglected. More often than not he needed reminders to shower, wash his clothes, change his linens, buy soap and toilet paper, etc. His hygiene was particularly problematic during the summer months when he tended to overdress and sweat profusely. And occasionally when he attended the Postgraduate Center, he was sent home to shower as his body odor was offensive.

His apartment, was frequently filthy with overflowing garbage, dirty dishes piled in the sink, food containers left out, and roaches or mice.

Within months of living in a supportive apartment it was clear to Community Access staff, the ICM, Postgraduate staff and Mr. Gordon's mother that he needed a more intense level of supervision. However, Mr. Gordon refused to move to a supervised residence. When this topic was broached, he would threaten to leave Community Access altogether and move to a hotel.

That being the case, staff created contracts with Mr. Gordon: if he kept his appointments, tended to his daily living needs and complied with medications, he could remain in his apartment. The rules were discussed with Mr. Gordon in meetings involving at least his ICM and sometimes staff from the Postgraduate Center and his mother, but never his private psychiatrist. Typically, these sessions would have the desired effect. Mr. Gordon would become more compliant. These periods of compliance

were short–lived, however. And when Mr. Gordon was confronted with his lapses and the need for a move to a more supervised setting, he would cite the pressures of college which he was attending part–time (e.g., "whose apartment wouldn't be a mess during final exams?") and beg for one more chance.

Eventually, Mr. Gordon was moved to one of Community Access' intensive supportive residences, where staff would visit him daily. Conditions did not significantly improve.

Eventually, however, Mr. Gordon was moved to one of Community Access' intensive supportive residences, where staff would visit him daily. This occurred in July 1993 and was seen as a compromise: it was clear Mr. Gordon was not doing well with several visits a week, but he refused to move to a 24 hour–a–day supervised residence. His level of compliance and self–care did not appreciably improve in his new apartment, even with daily staff visits. Periodically, Mr. Gordon complained of feeling tired or lethargic and staff noticed he engaged in ritualistic/compulsive behavior. On two occasions, once in 1992 and again in 1993, Mr. Gordon went to plastic surgeons to have hair transplanted from his scalp to face, apparently in response to his continued delusions about his appearance. Service providers learned of these incidents after the fact. However, they did not effectively probe why Mr. Gordon arranged for the procedures, where they occurred, how they were financed or what they signified, in terms of Mr. Gordon's ongoing treatment.

During his two and one–half years with Community Access, Mr. Gordon's private psychiatrist attempted to address Mr. Gordon's symptoms of delusions, depression and obsessive behaviors with changes in medications. While Mr. Gordon initially refused increases in his Clozaril level of 350 mg. daily, he did agree to trials of Wellbutrin (in November 1992), Prozac (in December 1992), and Klonopin (in April 1993) as adjuncts to his Clozaril therapy. However, they had little impact and were discontinued, usually within a month.

Despite the array of service providers involved in Mr. Gordon's life, there were aspects of Mr. Gordon's care which were not addressed or were poorly managed.

In mid–1993, Mr. Gordon allowed his Clozaril to be increased, up to 500 mg. daily. However, at this level the psychiatrist noted an increase in Mr. Gordon's obsessive/ritualistic behaviors—spontaneous singing, humming, and bizarre patterns of handling objects. As such, he slowly decreased the Clozaril dose to 200 mg. and started Mr. Gordon on Orap, an antipsychotic which was titrated up to 6 mg. daily by December 1993.

Falling Through the Cracks

Despite the array of service providers involved in Mr. Gordon's life, some of whom had daily contact with him, there were aspects of Mr. Gordon's care which were not addressed or were poorly managed, including his physical health, medication management and issues pertaining to family dynamics.

■ Physical Health

Upon release from Columbia Presbyterian Hospital in December 1991, Mr. Gordon was scheduled to attend a medical clinic at the hospital for follow up of his elevated liver function test (LFT) results. This apparently did not occur.

Significantly elevated LFT values were found when Mr. Gordon's care was transferred to a private psychiatrist in August 1992. Upon receipt of the initial complete blood work, the psychiatrist noted the elevated levels and indicated in the record that he would follow up during the next visit. He did contact Columbia Presbyterian Hospital and learned that Mr. Gordon had chronically elevated LFTs, but he did not reorder liver function tests during the next visit, although he did order routine Clozaril blood work.[5]

The psychiatrist did not order regular complete blood work-ups to monitor Mr. Gordon's fluctuating liver enzymes and elevated cholesterol levels.

In December 1992, the psychiatrist again recorded his plan to check the LFTs during the next visit; but he didn't. The next complete blood work–up was done in October 1993. At that time, the LFTs were within the normal range. However, Mr. Gordon's cholesterol level was noted to be abnormal and the laboratory report indicated that the value found was associated with a moderate risk for coronary heart disease. It does not appear that the psychiatrist communicated this information to any other provider in Mr. Gordon's life. Nor did he order any further complete blood work–ups to monitor Mr. Gordon's fluctuating liver enzymes and elevated cholesterol levels.

Soon after discharge from Columbia Presbyterian Hospital in late 1991, Mr. Gordon visited a private medical doctor for a physical examination. The examination was needed as part of an application for funding for services through the State Office of Vocational and Educational Services for Individuals with Disabilities (VESID). The physician noted an elevated blood pressure of 140/100. He informed the Visiting Nurse Service ICM and requested that Mr. Gordon return in a month for a follow–up examination. Mr. Gordon refused, despite the ICM's urging. The ICM, who was a nurse, and the physician agreed that the ICM should take several blood pressure readings over the next four to six weeks and inform the physician of the results.

The ICM followed the physician's instructions. Mr. Gordon's five blood pressure readings taken by the ICM in the spring of 1992 ranged between 140/100 and 150/120. The physician was informed of the significantly elevated results and advised the ICM, who informed Community Access staff, that Mr. Gordon may require medication to control his hypertension. Mr. Gordon, when informed, downplayed the significance of his hypertension; he also refused to sign any release of information forms so staff could access health care information.

The issue of hypertension was never forthrightly addressed by service providers.

Following this, the issue of hypertension was never forthrightly addressed by service providers, although case managers periodically reminded him to eat healthy foods and stay away from greasy ones. No further monitoring of Mr. Gordon's blood pressure was undertaken, even though his psychiatrist's weekly progress note forms had space allocated for recording vital signs, including blood pressure. The psychiatrist never took blood pressure readings.

In the spring of 1993, Community Access staff noted that Mr. Gordon had lost considerable weight. Aside from telling him to eat three

[5] Although weekly blood work is required for Clozaril therapy, LFTs are not included in this standard test.

meals a day, there was no concerted effort to determine what his weight was, whether it was within the ideal range, what was the cause of the weight loss, and whether he was eating in a healthy manner.

The psychiatrist, who recorded Mr. Gordon weighing 214 pounds (at 5'7" tall) when he first enrolled in private therapy in 1992, also commented on a significant weight loss in an October 1993 progress note. However, he did not weigh Mr. Gordon at that time or encourage him to see a medical physician. The issue of weight loss or diet was not commented on again.

From the onset, there were concerns about Mr. Gordon's medication compliance.

In the spring of 1994, Mr. Gordon confided to Community Access staff that for several days in February he drank beer as he was depressed, and that it made him feel "sick" and "sore all over." This episode of an apparent drinking binge was significant in that Mr. Gordon rarely, if ever, consumed alcoholic beverages, according to his family and case managers. Yet the episode, and Mr. Gordon's reaction to it, were not communicated to his psychiatrist or other service providers for further exploration and monitoring.

■ Medication Issues

From the beginning of his residency with Community Access there were concerns over Mr. Gordon's medication compliance. The concerns prompted staff to establish a system whereby Mr. Gordon would report to a supervised residence to take his medications under staff's watchful eye. Staff even rearranged Mr. Gordon's medication times to accommodate his school schedule.

Notwithstanding his periodic failures to report for medications, other factors combined to undermine attempts to ensure that Mr. Gordon received his medications as prescribed by his psychiatrist. These included: poor communication between the psychiatrist and Community Access staff, a lack of vigilance in monitoring Mr. Gordon's ingestion of medications, and sloppy or erroneous record keeping.

Mr. Gordon's psychiatrist did not regularly communicate with Community Access staff about Mr. Gordon's medication regimen. He would write prescriptions for Mr. Gordon, who would supposedly fill the prescriptions and give the medications to Community Access staff for storage and dispensing. The lack of direct communication between these parties led to confusion, medication errors, and probably noncompliance.

The lack of direct communication between the psychiatrist and residence staff led to confusion, medication errors, and probably noncompliance.

For example, during the summer of 1993 while Mr. Gordon's Clozaril was being titrated down, Community Access staff became confused about what his medication regimen was. They called the psychiatrist's office, spoke with his assistant and learned that while they were giving Mr. Gordon Clozaril 400 mg. and Klonopin 1 mg. daily, in actuality he was to receive Clozaril 300 mg. daily. The Klonopin, they learned, had been discontinued nearly three months earlier.

On another occasion in late 1993, the psychiatrist increased Mr. Gordon's Orap from 2 mg. to 4 mg. to 6 mg. over a three-month period.

Community Access records indicate that Mr. Gordon was administered only 2 mg. of Orap daily during this three–month period.

Clozaril levels suggested that Mr. Gordon may have been "cheeking" his Clozaril. It is not clear if these test results were shared with Community Access staff by Mr. Gordon's psychiatrist.

On yet another occasion in late 1993, Mrs. Gordon became concerned that her son might be "cheeking" his medications (Clozaril and Orap). She asked the psychiatrist if it would be possible to crush the pills into powder form, mix the powder with liquid and have her son drink the mixture to ensure he received the medications. The psychiatrist, sharing the mother's concerns, agreed with her suggestion, and Mrs. Gordon informed Community Access of her idea and the physician's concurrence.

Community Access staff, however, noting that Mr. Gordon was resistant to taking Orap, which was recently added to his drug regimen, and not the Clozaril, assumed that the psychiatrist wanted only the Orap crushed and dispensed in liquid form. They crushed and dispensed the Orap in liquid form; they continued to give Clozaril in tablet form. The psychiatrist wanted both given in liquid form.

Earlier Clozaril levels had suggested that indeed Mr. Gordon may have been "cheeking" and later discarding his Clozaril. In the spring of 1993, when Mr. Gordon was supposedly receiving at least 400 mg. of Clozaril daily, a Clozaril-level blood test could detect none of the medication in his system. A repeat test done one month later and after his dose had been increased to 500 mg. indicated a subtherapeutic level of 69 (normal range: 100-700). It is not clear if these test results were shared with Community Access staff by Mr. Gordon's psychiatrist. But it is clear that Clozaril levels, which would tend to indicate medication compliance, were not conducted again during the last year of Mr. Gordon's life.[6]

During a site visit to the supervised residence where individuals with medication–compliance problems received medications, Commission staff noted that medication staff do not inspect individuals' mouths or talk with them following the ingestion of pills to ensure they swallowed them. Staff reported that they are not required to do so.

While Community Access may not have had direct knowledge of the wishes of Mr. Gordon's psychiatrist or access to some of the information which he had in his possession, it also appears that the psychiatrist wasn't fully aware of information which Community Access had.

Mr. Gordon's psychiatrist believed Mr. Gordon was fairly medication compliant.

Upon interview, Mr. Gordon's psychiatrist reported to Commission staff that he believed Mr. Gordon was fairly medication compliant-receiving crushed medications in liquid under staff's supervision. In monthly summaries of Mr. Gordon's medication compliance for the last several months of his life, the Community Access case manager rated him as "compliant." However, medication administration records kept by staff of the supervised residence where Mr. Gordon received his medications indicated that he was not compliant. For example, during the months of January through May 1994 when his case manager rated

[6] It should be noted that following Mr. Gordon's death, approximately 70 tablets of what appeared to be Clozaril were found in his clothing.