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

A Report

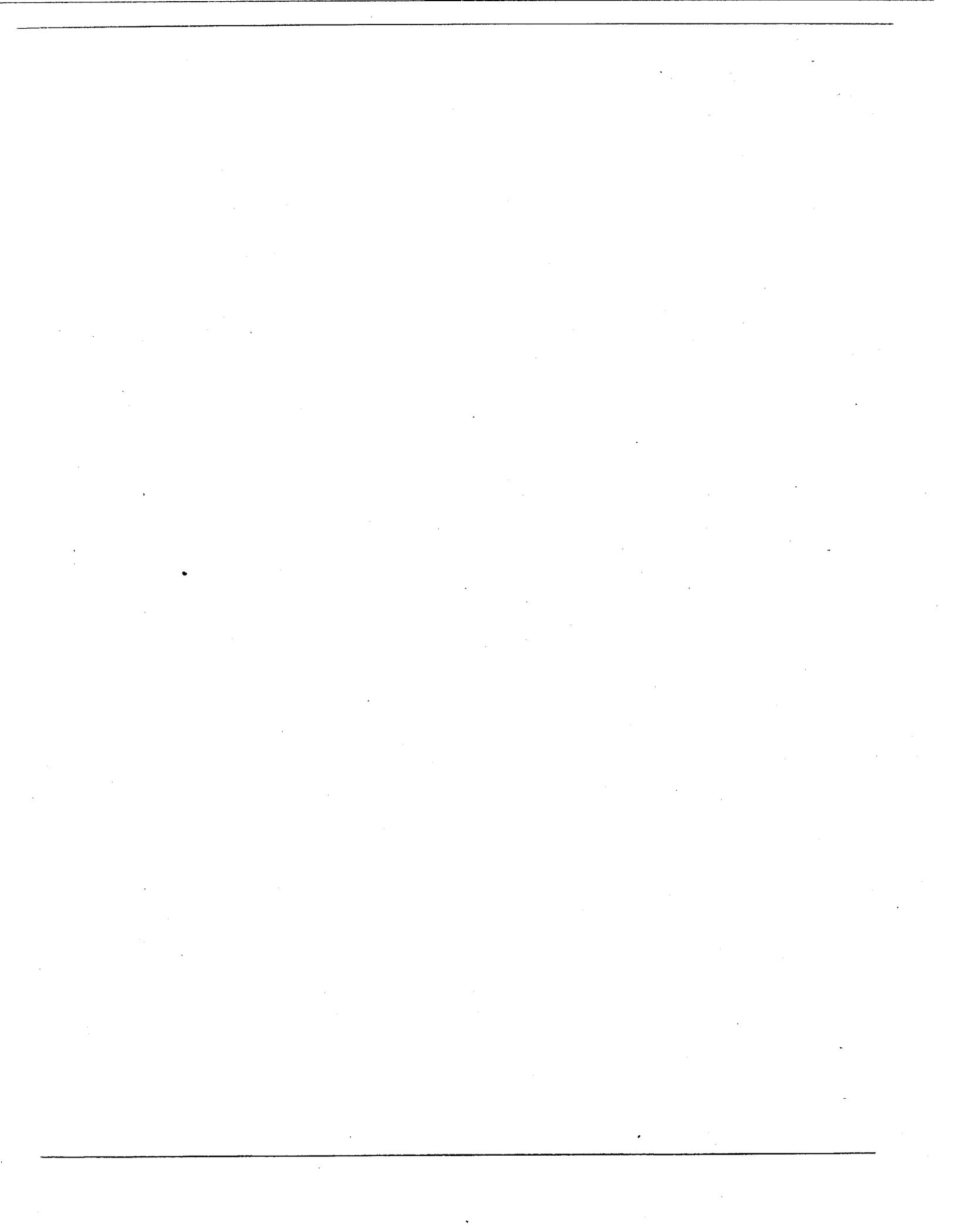
by the

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

and the

Mental Hygiene Medical Review Board

August 1995



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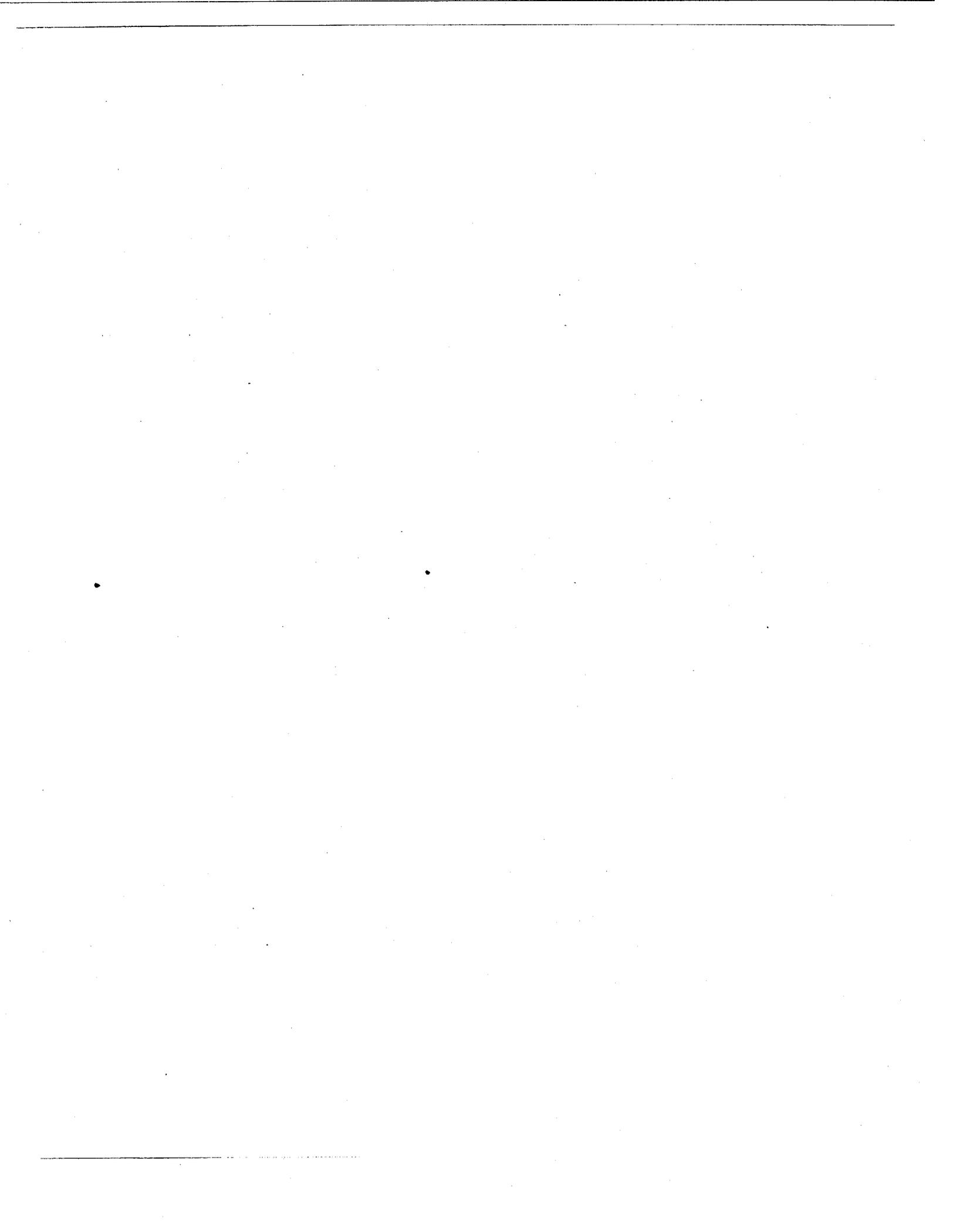
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August 1995



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.)

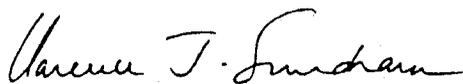
To a certain extent, the conditions Mr. Gordon endured in the quest of his dreams were the result of his own strong resistance to accepting his mental illness and the advice of his care providers concerning his need for treatment and supervision. (Report pp 18-19.) To a considerable extent, however, 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.

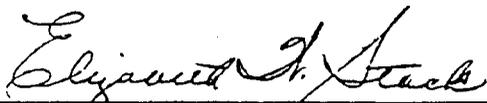
In this report, the Commission offers recommendations on how facilities could revise and revamp their policies and practices to better manage and reduce this risk of failure through enhanced service planning and interagency coordination. (Report pp. 21-22.)

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.

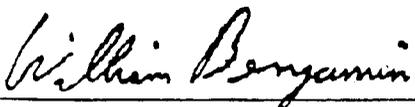
The findings, conclusions and recommendations contained in this report represent the unanimous opinions of the members of the Commission.



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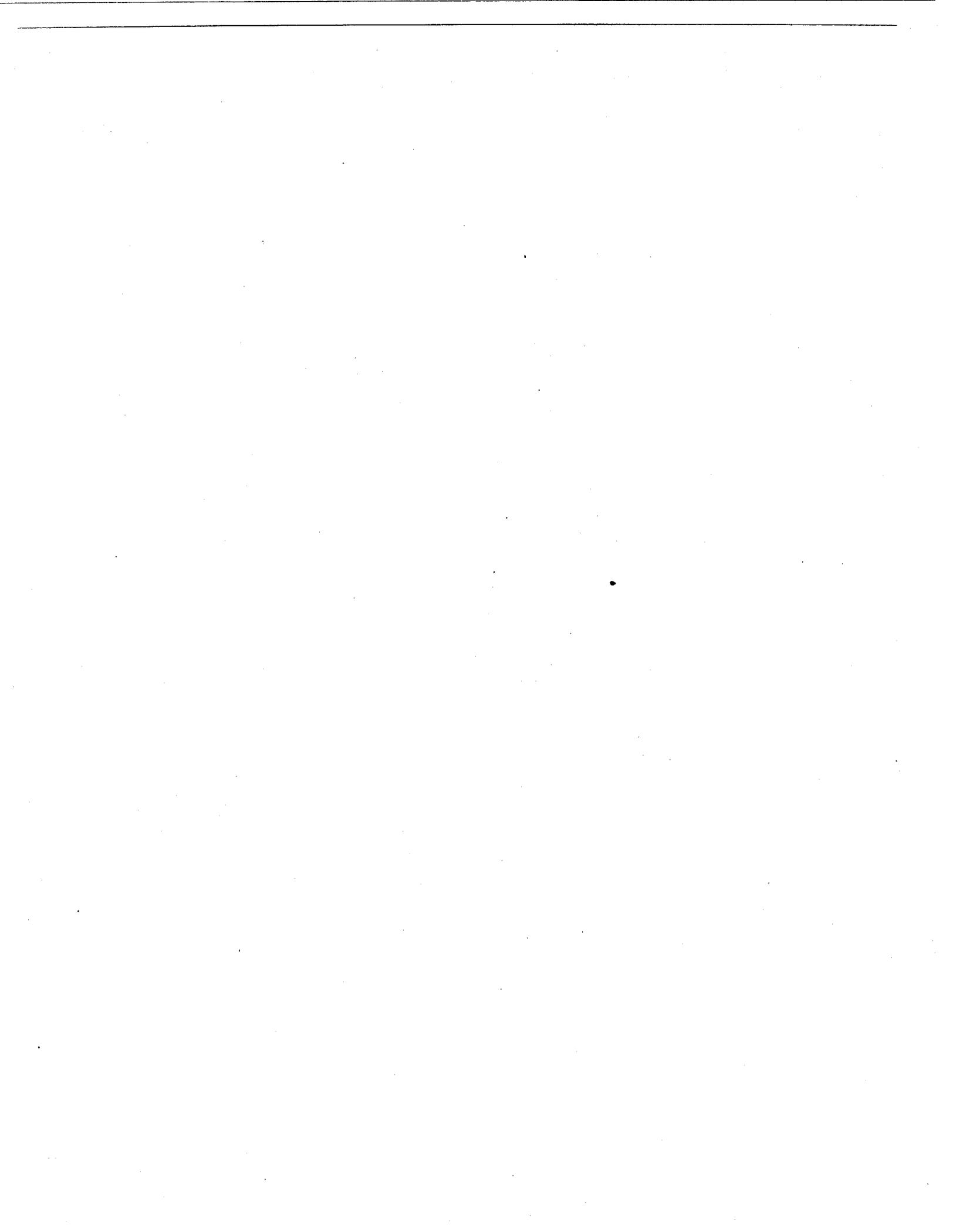


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Responses to Commission's Draft Report:

- Office of Mental Health
- Community Access, Inc.
- Postgraduate Center for Mental Health
- Visiting Nurse Service of New York



Introduction

On May 28, 1994, Jacob Gordon¹ 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 died shortly after noon on May 29 with his family at his bedside.

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

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.

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

- 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.

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.

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

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.

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

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.

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

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.

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

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, 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.

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

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.

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.

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.

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."

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.

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

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.

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.

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

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 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.

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.

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

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.

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

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.

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.

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

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

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.

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, 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.

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.

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

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

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

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.

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.

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.

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

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.

During the first four to five months of 1994, residence records indicate Mr. Gordon missed taking medications nearly one-third of the time.

him as medication "compliant," medication administration records indicate Mr. Gordon missed medications:

- ten days in January;
- ten days in February;
- ten days in March;
- nine days in April; and
- ten days through May 23.

On a number of occasions during this period, Mr. Gordon missed taking his medications on two consecutive days, meaning that 72 hours elapsed between his doses of Clozaril. According to Sandoz, which manufactures Clozaril, when individuals are initially started on Clozaril or when they briefly terminate Clozaril therapy for two or more days, the dose they should be started on, or restarted on, should be 12.5 mg. once or twice a day. This is to prevent the possibility of orthostatic hypotension and syncope (drop in blood pressure and fainting) which is a risk associated with Clozaril; in rare cases (one in 3,000), the patient may also experience cardiac and respiratory arrest. Once the individual has been safely started or restarted on the low dose of Clozaril, the medication is to be titrated upward.

This was not done in Mr. Gordon's case. His psychiatrist was unaware that he was missing medications on consecutive days. In fact, during the first four to five months of 1994 when Mr. Gordon was missing medications nearly one-third of the time, it appears, based on the psychiatrist's and Community Access' records, that his psychiatrist was contacted only once (in mid-March) and told that in the previous two weeks Mr. Gordon had missed medications on two occasions each week.

■ Family Dynamic Issues

The clinical records suggest a tension between Mr. Gordon and his family, one which impacted on providers involved in his life while he resided with Community Access, but one which was not forthrightly addressed.

The clinical records suggest a tension between Mr. Gordon and his family, one which impacted on him, his family and the providers involved in his life, but one which was not forthrightly addressed.

Mr. Gordon frequently complained about his mother being overinvolved in his affairs. On at least one occasion he asked that she not participate in one of his case conferences. And on one occasion his family asked for a case conference, but without Mr. Gordon's participation. On other occasions Mr. Gordon did allow family members to be involved in case reviews; however, he also asked that staff not share too much information about him with his family. Yet when Mr. Gordon experienced problems, with a roommate for example, he would call his family for assistance rather than alerting his case managers.

With both Mr. Gordon and his family giving conflicting signals over the level and nature of family involvement in care, service providers were in a quandary which went unresolved and influenced their actions.

Mr. Gordon's therapist from the Postgraduate Center, for example, did not believe that his enrollment in the program was clinically

In the absence of a bona fide plan to address family dynamic issues, Mr. Gordon's parents were placated by some providers, utilized by other providers to pressure Mr. Gordon to comply with treatment (which fueled his resentment over their role in his adult life), and inappropriately used to fill a void of advocacy on Mr. Gordon's behalf when service providers should have been speaking directly and clearly to each other.

appropriate, given his lack of willingness to attend and participate in therapy. Upon interview with Commission staff, she reported that the only reason Mr. Gordon continued to be enrolled in the program, despite his displeasure with the program, was because of his mother's insistence.

And despite Mr. Gordon's protests that his mother was overinvolved in his care, Community Access abdicated its responsibility to interact directly with Mr. Gordon's psychiatrist by asking Mr. Gordon's mother to intervene and ask the psychiatrist's secretary to call Community Access when Mr. Gordon failed to keep an appointment so that Community Access could follow up.

The psychiatrist himself, who never attended case conferences with Community Access or the Visiting Nurse Service, used Mr. Gordon's parents to exert, as he put it in one progress note, "pressure" on Mr. Gordon to accept increased medication dosages, despite Mr. Gordon's resentment over what he perceived as the overinvolvement of his family in his case.

In the absence of a bona fide plan to address family dynamic issues in Mr. Gordon's case and the absence of sound communication among service providers, Mr. Gordon's parents were placated by some providers through Mr. Gordon's retention in inappropriate services, utilized by other providers to pressure Mr. Gordon to comply with treatment (which fueled his resentment over their role in his adult life), and inappropriately used to fill a void of advocacy on Mr. Gordon's behalf when other parties should have been speaking directly and clearly to each other. Sometimes this advocacy role assumed by the family even further muddied the waters, as in the "crushed medication incident" when information on Mr. Gordon's medication was not clearly communicated from the psychiatrist to Community Access via Mrs. Gordon.

The Final Months and Days

In early 1994, Mr. Gordon was living in an intensive supportive apartment receiving nearly daily visits from Community Access staff and weekly visits from his ICM. According to the records he was to receive Clozaril 200 mg. and Orap 6 mg. daily.

His pattern of noncompliance with treatment plans continued. As mentioned earlier, he missed medications nearly one-third of the time between January and May 1994. He also ceased attending programs at the Postgraduate Center, although he told his ICM and Community Access case manager that he was attending periodically. He also missed or arrived late for blood tests and sessions with his private therapist. His attention to hygiene and sanitary conditions in his apartment was also severely wanting.

In April 1994, Mr. Gordon was terminated from the Postgraduate Center, after having not attended since December 1993. The termination was reportedly agreeable to Mrs. Gordon who indicated her son was completing college work necessary for his May 1994 graduation.

Following this, in May 1994, Mr. Gordon became even more socially isolative, avoiding case managers who came to visit.

On May 25, 1994, Mr. Gordon's case manager visited him in his apartment. Mr. Gordon appeared to be sweating profusely, he also complained of weakness, depression, and extreme lethargy.

On May 26, the case manager took Mr. Gordon by cab to his psychiatrist's office. Following the visit with the psychiatrist, Mr. Gordon asked to be moved to a supervised residence, which was completely out of the ordinary for Mr. Gordon. The case manager said he would speak with his supervisor.

He increasingly complained of depression and loneliness; his psychiatrist recorded that Mr. Gordon appeared to be becoming more paranoid. On May 19, 1994, Mr. Gordon agreed to an increase in Clozaril to 300 mg. daily. However, over the next seven days Mr. Gordon took his medications on only three occasions.

On Wednesday, May 25, 1994, Mr. Gordon's case manager visited him in his apartment. Mr. Gordon appeared to be sweating profusely, he also complained of weakness, depression, and extreme lethargy. The case manager called Mr. Gordon's psychiatrist to report his observations. The psychiatrist informed the case manager that this was not unusual for Mr. Gordon and that Mr. Gordon should be encouraged to attend their regularly scheduled appointment the next day, May 26.

On May 26, the case manager again visited Mr. Gordon who was "sweating and malodorous." Mr. Gordon complained of aching all over. The case manager reminded Mr. Gordon of his need to shower and attend his psychiatric appointment. Later that day in follow-up calls to the psychiatrist's office, the case manager learned that Mr. Gordon had not shown for his appointment.

The case manager went to Mr. Gordon's apartment. Mr. Gordon was sweating and complaining of being so weak he had trouble walking. The case manager took Mr. Gordon by cab to his psychiatrist's office and reportedly told the assistant about Mr. Gordon's physical complaints. Upon interview, the assistant denied being told of the patient's physical complaints. The psychiatrist, who met only with Mr. Gordon and not the case manager who for the first time in nearly two years accompanied Mr. Gordon to the office, informed Commission staff that Mr. Gordon appeared depressed, but aside from the depressed mood, he seemed to be his usual self. The psychiatrist discontinued Mr. Gordon's Orap prescription and instead ordered an antidepressant, Paxil 20 mg. daily; he also renewed Mr. Gordon's prescription for Clozaril 300 mg. Blood drawn on this day, the results of which were available after May 27, indicated that Mr. Gordon's white blood cell count was slightly elevated above normal limits at 13.4/cu.mm.⁷

Following the visit with the psychiatrist, Mr. Gordon confided to his Community Access case manager that he never felt so bad, and he asked to be moved to a supervised residence, which was completely out of the ordinary for Mr. Gordon. The case manager said he would speak with his supervisor.

The case manager and Mr. Gordon filled his prescriptions at a pharmacy and Mr. Gordon took a cab to his family's apartment.

The next morning, May 27, the Community Access case manager went to Mr. Gordon's apartment, but he was not home. The worker called Mrs. Gordon who reported that her son was at her home, sleeping. Mrs. Gordon expressed concern that Mr. Gordon appeared to be decompensating. She was also concerned that he had not been taking his medica-

⁷ Normal WBCs range between approximately 4.1 to 10.9/cu.mm. Over the years, Mr. Gordon's WBC usually ran between 6.2 to 9.0/cu.mm.

tions regularly. At her request, Community Access staff and Mr. Gordon's ICM began devising a daily schedule of escorts to ensure that Mr. Gordon went to the supervised residence to take his medications.

The case manager again visited Mr. Gordon's apartment that afternoon. According to the case manager, Mr. Gordon's eyes were dark, he was hunched over, and complained of hurting all over. He moved and spoke slowly, and said he did not feel well. He reported that he had already taken his daily medications. Concerned over Mr. Gordon's depression, the case manager spoke with his supervisor, and then with Mr. Gordon. Mr. Gordon denied any suicidal ideation. The case manager reviewed the beeper procedure with Mr. Gordon, should he need someone in an emergency, and took Mr. Gordon's remaining medications (the prescriptions he had filled the day before) for storage in the supervised residence.⁸

Between 8 and 9 o'clock on Saturday morning, May 28, the superintendent of Mr. Gordon's apartment building found him wandering the hallway, wearing only underwear and a shirt. The superintendent reported that Mr. Gordon was acting strangely, as if he were drunk; he was chanting and singing loudly.

The superintendent did not have a key to Mr. Gordon's apartment and his attempt to gain access through a window via the fire escape was unsuccessful. The superintendent tried calling Community Access, but no one answered the phone. (It was later learned that he dialed the number for the main office, which was closed, and he did not have a telephone number for nonbusiness hours or emergencies.)

Unable to gain access to Mr. Gordon's room and unable to contact Community Access staff, the superintendent left Mr. Gordon with some neighbors milling in the hallway and went about other business.

According to neighbors, Mr. Gordon knocked on doors and was chanting. Someone evidently gave him a sheet because after noon the superintendent found him covered with a sheet lying on the hallway floor outside his room. Mr. Gordon was incontinent, moaning and unresponsive.

The superintendent called 911 and Mr. Gordon was taken to Beth Israel Medical Center. A case manager visited Mr. Gordon's apartment shortly after 1 p.m. He wasn't home, so the case manager returned to Community Access' office. Shortly thereafter, Community Access was informed of Mr. Gordon's admission to Beth Israel Medical Center.

The Final Hours

Upon arrival at the hospital, Mr. Gordon's temperature was 102.4°. He was responsive only to painful stimuli and his vital signs fluctuated: blood pressure ranged from 96/45 to 135/95, respirations from 28 to 50, and pulse above 130 to 135.

On Saturday morning, May 28, the superintendent of Mr. Gordon's apartment building found him wandering the hallway. The superintendent reported that Mr. Gordon was acting strangely and tried calling Community Access, but no one answered the phone. The superintendent went about other business. After noon the superintendent found him covered with a sheet lying on the hallway floor outside his room. Mr. Gordon was incontinent, moaning and unresponsive.

A count of the Paxil and Clozaril tablets after Mr. Gordon's death indicated that three days' worth of the Paxil were missing and one day's worth of the Clozaril was missing. Mr. Gordon had access to the new prescriptions for only two days. The pill count suggests he may have taken too little Clozaril and too much Paxil.

Despite cooling measures, Mr. Gordon's temperature increased to more than 107° and he evidenced signs of multisystem organ failure.

Laboratory tests indicated abnormally high levels of glucose, creatinine and total protein. Phosphorus, magnesium, amylase, BUN, CPK and LDH levels were also significantly elevated. The potassium level was notably low. Blood work also indicated a slightly elevated alcohol level.

Mr. Gordon was assigned the diagnoses of coma of unknown etiology and rule out: diabetic ketoacidosis, myocardial infarction and drug overdose. Neuroleptic Malignant Syndrome (NMS) was added to the list of possibilities when his medication history became known to hospital staff.

Mr. Gordon was intubated, placed on mechanical ventilation and, in the opinion of the Commission's Medical Review Board, aggressively treated for the various possibilities his symptoms suggested, including NMS. As test results came back, they were negative for infection, heart attack and illicit drug use.

Despite cooling measures, Mr. Gordon's temperature increased to more than 107° and he evidenced signs of multisystem organ failure.

In the early morning of May 29, Mr. Gordon suffered cardiac arrest. He was successfully resuscitated, but his condition deteriorated and he died shortly after noon.

Cause of Death

Upon autopsy, Mr. Gordon's death was attributed to Neuroleptic Malignant Syndrome (NMS).

Upon autopsy, Mr. Gordon's death was attributed to Neuroleptic Malignant Syndrome (NMS). The syndrome—a cluster of symptoms, including hyperthermia, changed mental status, fluctuating vital signs and muscle rigidity, in the absence of other—drug induced, systemic or neurological illnesses—is seen in two-tenths of one percent of individuals treated with neuroleptics.⁹ Some of these patients claimed that they also felt a sense of impending doom.¹⁰ NMS usually occurs within the first 30 days of the initiation of neuroleptic treatment; however, cases have been reported involving patients on neuroleptics for longer than 30 days.

Treatment usually involves the cessation of the neuroleptic medications, fever management measures and the administration of muscle relaxants. With increased knowledge about the syndrome, early detection and prompt treatment, survival rates have increased. However, if left untreated, NMS results in death in approximately 30 percent of the cases. Unfortunately, there are few predictors as to who is at risk for NMS; the most common risk factor is a prior episode of NMS.

In Mr. Gordon's case, it is not possible to determine with certainty whether the NMS was associated with his sporadic intake of Clozaril, or the initiation of Paxil which was started on May 26, or the combination of both. It is also unknown whether Mr. Gordon's complaints of physical discomfort—lethargy, difficulty walking, sweating, etc.—prior to his May 26 visit to the psychiatrist were symptoms of the onset of NMS.

⁹ Caroff, S. N. & Mann, S. C. (1993). Neuroleptic Malignant Syndrome. *Medical Clinics of North America*, 77, 185-202.

Simon, H.B. (1993). Hyperthermia. *The New England Journal of Medicine*, 329, 483-487.

¹⁰ Rosebush, P. (1994). What is Neuroleptic Malignant Syndrome and How is it Treated? *The Harvard Mental Health Letter*, 11.

Conclusion

While the Commission and the Mental Hygiene Medical Review Board concurred that Mr. Gordon died as a result of Neuroleptic Malignant Syndrome, why and when Mr. Gordon began experiencing NMS is not clear. It is clear, however, that there were a number of breakdowns in the care and treatment provided to Mr. Gordon that contributed to the conditions under which he died at age 35 on May 29, 1994.

A generation ago, a patient like Mr. Gordon could very likely have spent his youth in a state psychiatric hospital once he was hospitalized for the treatment of mental illness.

A generation ago, a patient like Mr. Gordon could very likely have spent his youth in a state psychiatric hospital once he was hospitalized for the treatment of mental illness. In return for the "one-stop shopping" of a state institution, Mr. Gordon would have given up much of his privacy and day-to-day control over his life. Instead, Mr. Gordon spent four relatively brief periods of time in psychiatric hospitals over the past eight years of his life and lived in the community for most of this time.

A highly intelligent man, he did not view himself by his diagnosis of mental illness but insisted on the right to live his life as he saw fit. To a considerable extent, the mental health system and its many service providers attempted to accommodate his wishes while also continually advocating for a greater degree of supervision than he would accept. Mr. Gordon also had the benefit of the constant support and advocacy of his family, whose concerns he did not always share and whose involvement he sometimes protested. The combined efforts of his family and a variety of public and private health and mental health providers enabled Mr. Gordon to live with some degree of independence in the community while having access to the services and supports they thought were needed.

The combined efforts of his family and a variety of public and private health and mental health providers enabled Mr. Gordon to live with some degree of independence in the community.

On the surface, it would appear that each attempted to meet the challenge. Hospitals stabilized him in times of crisis. Case managers from his residential and intensive case management programs visited him frequently, if not daily. His psychiatrist saw him nearly weekly and regularly prescribed medications within appropriate dosage ranges. And the doors to his day program were always open. In the last three years of his life, more than \$140,000 in Medicaid funds alone were spent on Mr. Gordon's care; this does not include the full costs of his housing or the private payments to his private psychiatrist. During this period, at least ten service entities were involved in his life including Columbia Presbyterian Hospital's inpatient unit; its outpatient clinic; Community Access' supportive apartment program; Community Access' supervised residential program, which provided medication services; Community Access' social club; the Visiting Nurse Service; a private psychiatrist; a private internist; the Postgraduate Center's continuing day treatment center; and a pharmacy.

However, despite the considerable efforts made on his behalf, the mental health system and the individual service providers ultimately were not able to meet his needs. To some extent, his own strong

To some extent, his own strong resistance to accepting his mental illness and need for treatment and supervision undermined their efforts.

Beyond Mr. Gordon's own resistance, however, the sheer number of providers complicated the challenge of ensuring appropriate care and of keeping the lines of communication open among all who played a role in Mr. Gordon's life.

resistance to accepting his mental illness and need for treatment and supervision undermined their efforts.

- On many occasions, Mr. Gordon would refuse to meet with his case managers whose function it was to ensure he was receiving the services he required and to monitor his well-being.
- He refused to consent to giving his intensive case manager health data from his private physician.
- He refused medical care for hypertension and refused to release health care information to the staff who were working with him.
- He often refused to attend his day treatment program, eventually resulting in his leaving it.
- He did not want to participate in group therapy with other persons who suffered from mental illness.
- He refused to take the medications prescribed in the dosages that were recommended. Even when dosages were lowered as he requested, he often failed to appear when he was scheduled to receive medication, and failed to take some of the medications given to him when he appeared.
- He missed numerous appointments with his psychiatrist and failed to regularly appear for the blood tests required for the Clozaril he was taking.
- He would not maintain his personal hygiene and diet, or the sanitary condition of his apartment, and refused to live in a supervised community residence which could provide him with the assistance he needed in these areas.
- Finally, he did not want his family's continued involvement with his service providers, or their advocacy on his behalf.

Beyond Mr. Gordon's own resistance, however, the sheer number of residential providers, outpatient service agencies, case managers, private health and mental health providers complicated the challenge of ensuring appropriate care and of keeping the lines of communication open among all who played a role in Mr. Gordon's life. Not surprisingly, essential information about his medical condition and medication compliance was not communicated or effectively followed up.

- Conditions such as hypertension, elevated liver function tests, dietary needs and, on one occasion, an alcohol binge, went unattended.
- While he was failing to attend his day program, case managers apparently believed he was attending.
- While he frequently failed to appear to receive his medications from one provider agency, his case manager from another program believed he was compliant and his psychiatrist was not informed of the extent of his noncompliance.

There are thousands of individuals with serious mental illness living in the community who rely on the support of multiple service providers. 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 mental illness.

- While his psychiatrist wanted him to receive certain medications, the staff dispensing the medications were dispensing other medications or different dosages.
- When the psychiatrist wanted his medications crushed and mixed with liquid to ensure they were ingested, his orders were only partially followed due to miscommunication.
- Despite concern that Mr. Gordon might not be taking his medications as prescribed, staff monitoring the medications did not check for "cheeking" nor did the psychiatrist order blood level tests to confirm that therapeutic levels of the drug were being achieved.
- Mr. Gordon's complaints about his physical difficulties around May 26 were either not communicated to, or not appreciated by his psychiatrist, and he did not receive prompt medical attention.
- Finally, when Mr. Gordon was found in distress by the superintendent of his apartment building on May 28, the superintendent did not have an emergency number to call his residential provider and communicate Mr. Gordon's condition.

While Mr. Gordon's life and death present learning opportunities for those service providers directly involved in his care, his legacy is larger. His is the story of how well the service system responds to the challenge presented by persons with mental illness who disagree with the recommendations for treatment of their illness and refuse to follow the advice of clinical professionals.

With the reduction of over 80,000 state psychiatric center beds in the last 40 years and the proliferation of community-based residential and clinical services, there are thousands of individuals with serious mental illness living in the community who rely 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 mental illness. Community-based programs throughout New York State are entrusted with the care of such individuals.

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.

This risk was not well appreciated by the multiple service providers involved in Mr. Gordon's life who failed to effectively communicate with each other. While each saw a dimension of Mr. Gordon's life, no one knew the totality of his needs and assumed responsibility for addressing them.

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Recommendations

The risk presented in Mr. Gordon's case is one of which all service providers should be conscious. As such, the Commission recommends that the Office of Mental Health disseminate the report, *In the Matter of Jacob Gordon*, to all mental health service agencies as an in-service training tool and a vehicle to promote agencies' reflection and discussion about the adequacy of their existing policies and practices, and remedial action where needed.

The Office of Mental Health should disseminate the report, *In the Matter of Jacob Gordon*, to all service providers as a training tool and a vehicle for assessing how well they respond to similar and common situations wherein clients have multiple service providers.

- Where multiple agencies forge a treatment relationship with an individual who tends to be noncompliant with their recommendations, are there mechanisms in place to ensure that:
 - All the providers have an understanding of each other's specific role in service delivery?
 - All the agencies are aware of the potential areas of noncompliance (e.g., self care, medication management, health care, program attendance, etc.), and the relative risks of harm associated with each?
 - All providers agree on strategies of care, particularly around issues pertaining to noncompliance, and methods for monitoring the plan of care and compliance issues?
 - One agency is designated as the lead agency responsible for monitoring all aspects of the plan of care?
 - The agencies periodically meet to collectively review the individual's progress and the need to revise service plans and that such meetings occur not when the calendar dictates, but as the individual's needs dictate?
 - Where individuals receive services from a private psychiatrist or therapist who may be unable to attend periodic meetings, the lead agency keeps the psychiatrist/therapist fully informed on all aspects of the individual's care?
 - The agencies and significant others (e.g., landlords, families, consumers, etc.) have means of contacting each other when emergencies arise?
- Where medication compliance is an issue to the point of individuals requiring supervision at medication times, do agencies' policies ensure that:
 - The level of supervision is sufficient to assure the individual actually ingests his or her medications?
 - Blood levels are periodically drawn to monitor medication compliance?
 - Staff are sufficiently aware of both the psychiatric and medical hazards associated with noncompliance?
 - Prescribing physicians are consulted about instances of medication noncompliance?

The Commission also recommends that Community Access review supervised medication practices for its service recipients.

■ Alternative forms of effective treatment consistent with the patient's wishes have been adequately considered?

- When individuals develop signs or symptoms of illness, as Mr. Gordon did around May 26, which may be attributed to either a physical or psychiatric condition, does the agency act to ensure both a medical and psychiatric assessment?
- When the nature and extent of family involvement becomes an issue in care, do the agencies collectively address and resolve this with the same care and diligence they bring to bear on self-care, medication, health care, and other treatment issues?

The Commission also recommends that Community Access review supervised medication practices for its service recipients. In Mr. Gordon's case, it appears that he did not receive medications as prescribed by his physician; despite supervision, Mr. Gordon apparently "checked" medications; his treating physician was not kept fully informed of the extent of Mr. Gordon's known noncompliance, which could have had significant consequences psychiatrically and medically; and record keeping practices concerning Mr. Gordon's medication regimen and compliance were woefully inadequate.

Community Access should also review the wisdom of having medication noncompliant individuals leave their supportive apartments to report to a supervised residence to take medications. It would seem that the task of having to leave their apartments and walk several blocks—in good and inclement weather—creates a further impediment to ensuring compliance, particularly if the individuals are not escorted.

Additionally, Community Access should review the role of case managers serving individuals in supportive apartments who have difficulty with self-care skills. In Mr. Gordon's case, case managers visited him religiously, noted his difficulties maintaining sanitary conditions, and constantly reminded him to bathe, do his laundry, clean the apartment and take out garbage—reminders which, more often than not, were ignored. Rarely did case managers join him in the task of maintaining a sanitary environment by rolling up their sleeves and pitching in to help clean.¹¹

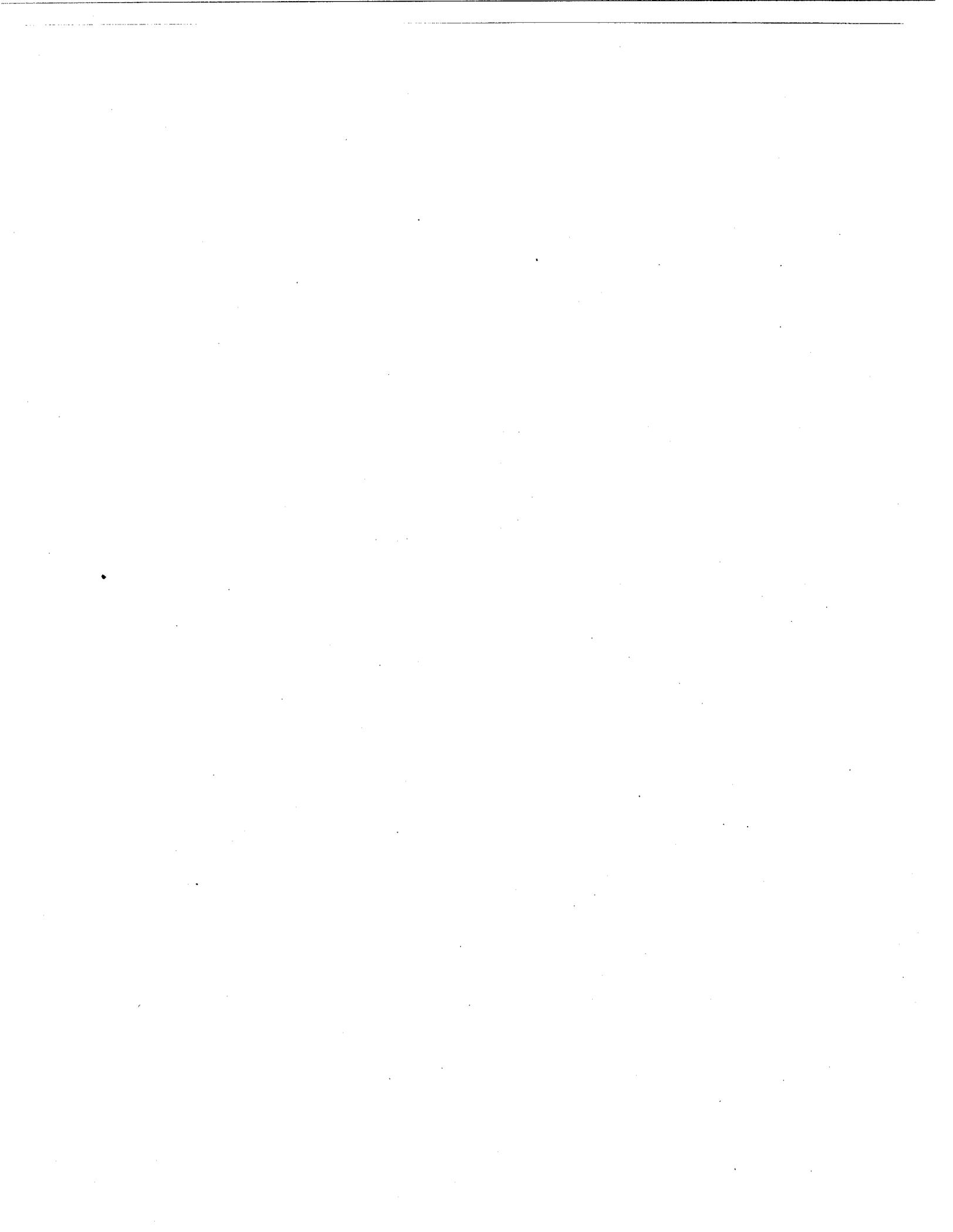
Community Access should review the role of case managers serving individuals in supportive apartments who have difficulty with self-care skills.

The Commission recognizes the value of residents' taking responsibility for their lives and the importance of case managers giving verbal guidance and clues in this regard—which they faithfully did in Mr. Gordon's case. The Commission, however, also believes there is a therapeutic benefit in case managers providing individuals hands-on assistance in such matters and serving as role models, furthering their service compact with clients, and assuring that service recipients are afforded a safe, clean environment.

¹¹ In its response, Community Access reports that staff did assist Mr. Gordon in attempting to maintain sanitary conditions. Progress notes pertaining to conditions in the apartment, however, suggest to the Commission that the assistance was not offered frequently enough.

Finally, as it appears that the intensive case manager from the Visiting Nurse Service was unaware of the extent of Mr. Gordon's noncompliance with medications and program attendance, the VNS should review the manner in which its case managers monitor these, and other, essential components of individuals' service plans.

Appendix





July 13, 1995

Honorable Clarence J. Sundram
Chairman, Commission on Quality of
Care for the Mentally Disabled
99 Washington Avenue
Albany, NY 12210-2895

Dear Mr. Sundram:

Thank you for sharing the Commission's draft report, *In The Matter of Jacob Gordon*. Its thoroughness and the care with which it is drafted convey a sensitivity not only to the life and untimely death of Mr. Gordon, but also to the considerable efforts of numerous health and mental health providers and staff. Many people attempted to help Mr. Gordon enjoy a quality of life in the community that was markedly different from what he would have experienced had he been institutionalized. The Commission's Report, together with the result of consultations conducted by this Office, confirm that Mr. Gordon valued his independence, and that he enjoyed and benefitted from being able to actively participate in decisions about his care. Yet, despite the efforts of Mr. Gordon himself and those of his providers of service, it was not enough to prevent this tragic outcome.

The Office of Mental Health concurs with the Commission's recommendation that communication among all service providers is paramount in meeting the health and mental health needs of individuals and agrees that the designation of a lead agency would be useful in coordinating treatment and services. It would be advantageous for such a lead agency to convene case conferences as necessary, particularly as an individual's needs change. Medical as well as psychiatric health issues should be addressed and appropriate medical expertise secured where needed.

Consequently, the Office of Mental Health believes that, despite the tragedy of Mr. Gordon's death, service providers can benefit from an understanding of the circumstances outlined in the Commission's draft report. We will utilize the report as a learning tool, and will assure its dissemination to state-operated and licensed programs.

Thank you again for the opportunity to review this report.

Sincerely,

Joel A. Dvoskin, Ph.D.
Acting Commissioner







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August 8, 1995

Mr. Thomas Harmon
New York State Commission of Quality of Care
for the Mentally Disabled
99 Washington Avenue
Albany, NY 12210-2895

Re: Response to Draft Report--In the Matter of Jacob
Gordon

Dear Mr. Harmon:

Thank you for the opportunity to review and comment on the CQC investigative report. Your researchers should be commended for their thoroughness in compiling such a meticulous study, one that obviously represents hundreds of hours of interviews and weeks of pouring over case records and other source documents.

The report has been reviewed by Community Access management staff, board members, and our program committee. It is our consensus that the issues raised by Mr. Gordon's experience in the mental health system, and his untimely death, represent much of what is wrong with the current system of support for people with psychiatric disabilities.

Empowerment: Choice vs Control

The comments below flow from a basic set of values that can best be described as the "empowerment model of recovery." These values center on personal choice and, concomitantly, personal responsibility. The role of staff in this model is to assist the individual who is seeking services to define for themselves their needs and wants and for staff to accommodate those desires to the greatest extent possible.

Our overall reaction to tragedy of Jacob Gordon's death is our regret that we did not give Mr. Gordon ample opportunity to exercise his most fundamental right: the right to choose the form of service he was to receive. If Community Access failed Mr. Gordon in any way, it was not through lack of effort or involvement in his life; rather it was not being more diligent as an advocate, something that he desperately needed and deserved.

We believe the service system needs overhaul, but not necessarily in the direction of better controls and more stringent oversight by providers. Instead, all consumers, especially those who "refuse to follow the advice of clinical professionals" need to be more involved in decisions affecting their lives, including selecting their own physician, medications, and living situations.

Of course there are limits, such as there are for all of us. But it is a rare situation that a consumer gets a full menu of available choices and a clear explanation of the costs and benefits associated with each one.

The CQC report assumes that Mr. Gordon was incapable of exercising free will and that it was incumbent upon the mental health system (and Community Access in particular) to enforce decisions made about Mr. Gordon's life by people whom he did not even select in the first place (the psychiatrist, for instance).

"To some extent, his own strong resistance to accepting his mental illness and need for treatment and supervision undermined their [the mental health system's] efforts..."

We would assert that Mr. Gordon was never allowed the opportunity to make decisions; and benefit or suffer from the consequences of those decisions. That is empowerment and it is the key to growth and maturity. The system-- including family members--"protected" Mr. Gordon from himself and infantilized him; a fact made abundantly clear by the detailed recounting of Mr. Gordon's treatment history in the CQC report.

Medication Compliance

Community Access questions the intent of the recommendations of the CQC report as pertaining to medication compliance. We do not believe it is the proper role of community-based, voluntary agencies to coerce people into taking medication to satisfy a "treatment plan." We will never condone this practice. Our medication monitoring system was set up for the benefit of consumers who wanted this assistance. It is not a policing function.

The issue was not that we should have done a better job crushing, liquifying and otherwise enforcing Mr. Gordon's compliance; rather we should have moved decisively either to help Mr. Gordon get off medication he clearly didn't want to take or advise him of the extreme health risks posed by his behavior and assisted him to find an alternative housing or treatment setting that could provide on-going medical oversight of the type we are not capable, or desirous, of providing.

Our practice is consistent with OMH medication guidelines. Three possible conditions are described in the guidelines: 1. individuals capable of self-medication; 2. individuals able to self-administer medication when reminded and closely supervised; and 3. individuals who refuse to take prescribed medication.

Upon entering Community Access, Mr. Gordon was considered to fit into category number 2: capable of self-administration when reminded and closely supervised. Over time however, Mr. Gordon did not consistently follow up as promised. In this situation, OMH guidelines state that the prescribing physician should be notified.

Contrary to suggestions made in the CQC draft report, Community Access staff did communicate with the prescribing physician about Mr. Gordon's unwillingness to take prescribed medication. This communication was difficult and was often funnelled through the doctor's staff. However, we assumed that the information was being conveyed and Mr.

Gordon's condition was being sufficiently monitored as a result of weekly blood work required with the Clozaril prescription.

OMH guidelines do not indicate what should happen once community residence staff advises a physician that a consumer is not taking prescribed medication. To us, the implied message is that once information about medication compliance is passed to the physician it becomes his or her responsibility to respond and provide guidance to our staff. The CQC must determine if this is the intent of the guidelines, and if so, where responsibility for action and decision making truly rests: physicians, social workers, family members or consumers?

Also to be noted: why was Clozaril, a medication requiring consistent compliance and monitoring, prescribed for a person who showed ongoing resistance and non-compliance, and who needed constant reminders to keep his weekly blood test appointments? Mr. Gordon consistently objected to taking this medication (even prior to moving to Community Access) and resisted any increases that were recommended by his physician deemed as necessary to decrease Mr. Gordon's symptoms and the negative side affects the medication caused.

Service Coordination

The CQC appreciates the challenge of adapting services to meet the needs of consumers:

"...there are thousands of individuals with serious mental illness living in the community...Most, like Mr. Gordon, are attempting to control the course and direction of their lives."

And as the CQC report rightly notes about Mr. Gordon's experience:

"His is the story of how well [i.e., poorly] the service system responds to the challenge presented

by persons with mental illness who disagree with the recommendations for treatment of the illness and refuse to follow the advice of clinical professionals."

This situation is further complicated when multiple service providers are involved. The CQC report advocates for a "...lead agency responsible for monitoring all aspects of the plan of care..."

While we agree with the following statement:

"...the risk of failure [i.e., the system's ability to provide support for consumers] escalates as the degree of disagreement and the number of service providers involved in the individual's life increases."

We disagree with the description of this situation:

"This risk was not well appreciated by the multiple service providers involved in Mr. Gordon's life who failed to effectively communicate with each other. While each saw a dimension of Mr. Gordon's life, no one knew the totality of his needs and assumed responsibility for addressing them."

We believe the lack of communication was not the cause of Mr. Gordon's death. Instead, the "breakdown" occurred months and years before Mr. Gordon arrived at Community Access when an array of programs, agencies and individuals became involved in his life without his active participation. Mr. Gordon had no "ownership" of this system, resisted involvement in it and because of this, what should have been minor health issues were left unattended and escalated into life threatening conditions and, eventually, a fatality.

The "breakdown in services," beyond Mr. Gordon's rejection of 90% of what was being offered, is the plain fact that there were too many people and agencies involved in his life. As one committee member observed, there was a

redundancy of services. Keeping all these people continuously updated--while at the same time Mr. Gordon was refusing to attend meetings, refusing to sign consent forms, and refusing medication--was virtually impossible.

Ultimately, there can only be one customer. The CQC report presents a dichotomy (which is widely accepted) that the system must maintain a balance between the obligation borne by community-based programs to "care" for persons with psychiatric disabilities and an individual's desire to "...control the course and direction of their lives."

This dichotomy flows from the medical model of treatment which emphasizes the role of professionals as both the ultimate decision-makers about a person's care and treatment and the group responsible for protecting the public from consumers who may pose a threat (and for protecting consumers from themselves). The medical model is really a "protection" model.

You cannot have both professional choice and consumer choice, because the professional is being held responsible and has control of the resources the consumer needs (housing, money, information, etc). The professional is being told "if you allow this to happen (e.g., refuse medication, discontinue a program, keep a sloppy apartment, etc), you will be held responsible by the oversight agencies." Under such a model any consideration of consumer empowerment is moot. Consumers can only be "empowered" to the degree professionals feel safe.

Service coordination needs to begin with the consumer as an informed, active participant in the process. It is the obligation of all the providers (and family members) to design a process for this to occur. It should not be our collective responsibility to design and enforce a treatment plan. Such a plan, no matter what level of communication exists, will not be successful in the long run.

Medical Care

Jacob Gordon died in a hospital from an unknown medical condition, probably neuroleptic malignant syndrome. We believe the issue of adequate on-going medical care is of paramount importance in this case and one that received scant attention in the report. Too often recipients of mental health services, who have some of the most pressing medical needs, are subject to the poorest quality of care.

In the last two days of Mr. Gordon's life he was clearly displaying symptoms of some type of ailment. In hindsight we can see this ailment was fatal. When staff at Community Access successfully engaged a physician to examine Mr. Gordon, he was deemed to be depressed and given a new prescription.

Was this diagnosis (or possible mis-diagnosis) the fault of the psychiatrist, who was a Clozaril specialist hired by Mrs. Gordon? Maybe, maybe not. Gordon's complaints were varied. He said he was depressed as well as being physically weak. Did his physical condition make him feel depressed? This could not have been determined without running a series of tests and the only physician to see Jacob within the last 72 hours of his life determined there was nothing physically wrong with him.

Again, possible human error; but Gordon's life should not have hung in such a perilous balance in the first place. Unwittingly, the system of care givers put Jacob at risk by a) not giving him a choice of service options, and then b) endangering him with the "treatment plan" that was imposed. If Mr. Gordon had been surrounded by treating professionals he had trusted he might still be alive today.

There can never be enough oversight and there will always be mistakes made by providers. Better that those mistakes are made on the side of giving people too much choice instead of too little. If that is done, we'll go a long way toward reducing the chances that someone will die because of our mistakes. Because giving people more choice instead of less will ultimately force us all to develop a more responsive system that consumers will use for preventive services, thereby reducing situations that result in emergencies like the one described here.

Self-Care Skills:

The Commission's Report indicates that "rarely did case managers join him in the task of maintaining a sanitary environment by rolling up their sleeves and pitching in to help clean."

On the contrary, our case notes indicate that in addition to "encouraging" and "instructing" Mr. Gordon around daily living skills, staff did "roll up the their sleeves" and assisted Mr. Gordon with his laundry, swept and washed the floor, washed dishes, and took out the garbage. He was escorted to the store to purchase soap and deodorant. Staff would also remain in his apartment to ensure that Mr. Gordon showered when he said he would.

In addition to these activities, where Community Access staff provided hands-on cleaning services to Mr. Gordon, numerous offers of accompanying him to the cleaners, laundry, etc, were rejected by him, as he requested to be allowed to do these activities independently.

Again, Mr. Gordon knew how to clean his apartment, bathe, shop, cook, and do a myriad other things much more complicated than this. Most of the time he simply didn't want to do them. Was this lack of motivation a "treatment" issue? Or was it reflective of Mr. Gordon's own sense of disempowerment and lack of control?

When it became obvious that Mr. Gordon could not maintain the standards of self-care needed to remain in a supportive apartment, it was recommended that he move into Access House, our 24 hour residence. The family rejected this suggestion and, given the dynamics involved (see below), it was difficult to implement any decision that they did not concur with. Further, the accusation was made by the family that we were motivated by financial considerations in seeking such a change.

Family Dynamics and Government Oversight

We believe the CQC report does not provide full flavor to the intensity of the ongoing interventions that Mrs. Gordon made on behalf of her son. Even more significantly, however, the report does not acknowledge the involvement of state officials from the Office of Mental Health who were drawn into participating in her son's treatment.

Oftentimes, if Mrs. Gordon felt frustrated or was dissatisfied by the response she was getting from program staff, she would contact OMH officials to directly intercede on her behalf, which they often did. OMH officials justified their actions by stressing the "importance of incorporating family members into the service planning of consumers." The message to the providers, who are certified and funded by these same officials, is clear.

Mrs. Gordon wasn't simply Jacob's mother; she was (and remains) a powerful and influential political force. Relatives with access to influence in the system is nothing new. Many relatives become involved with coalitions, politicians and policy making bodies precisely for the reasons Mrs. Gordon has: to increase the chances that their relatives will gain access to better quality care than might otherwise occur. Community Access itself, and many other mental health programs, were founded by friends and relatives of people with disabilities. Certainly, if I had a relative in the system I would do the same thing.

The CQC needs to define when this influence becomes pervasive and counter-productive. What guidelines can providers have to advocate on behalf of consumers without fear of retaliation or threats posed by influential family members or friends; and sometimes enforced by oversight agencies? There needs to be balance between involvement and undue influence.

Most certainly, no informed discussion of Mr. Gordon's experience in the mental health system can be considered complete without exploring this issue in more depth. The commission's report suggests that one agency or group

(presumably Community Access) should have stepped up its efforts to organize a better system of treatment for Mr. Gordon. While we object to the general premise of assuming control for Mr. Gordon's (or anyone else's) treatment, it was difficult to take any action on behalf of Mr. Gordon that was not consistent with the wishes of his family.

Conclusion

As a provider of supportive mental health services our goals should be to:

1. insure that each recipient is fully informed of the possible risks and benefits of all possible forms of treatment that are available.

2. build a supportive, trusting relationship with each recipient by recognizing their humanity and preserving their dignity,

3. protect the rights of each person as prescribed by law and regulation, and

4. advocate on behalf recipients to ensure that their opinions and wishes are fully considered in all decisions that effect their lives.

Community Access does not claim to have achieved all these goals, but we are taking the following steps:

- o actively involving our consumers in the hiring and training of staff,

- o providing consumers with full access to all information about their lives (including all case notes, treatment plans and referral documents),

- o training and hiring consumers to work as program staff and senior managers, and

- o recruiting consumers to sit on policy making bodies, such as our program committee and board of directors.

Within a few years, as a result of these efforts, we hope to transform Community Access' service delivery system into a genuine partnership with consumers. The system would feature choice, flexibility, advocacy, self-help and a comprehensive network of high quality services that would mirror the value system we are promoting here.

The CQC can play a powerful role in assisting in the transformation of the entire mental health system, if it so desires. Despite all the laws and regulations on the books, providers, in the end, operate out of "fear" for what they are going to get "blamed" for.

If, however, providers are held responsible for actively involving consumers in their treatment planning and giving them full access to their records, then providers will do this and the system will change. The result will be a higher quality of life for our customers and fewer tragedies of the type presented "In the Matter of Jacob Gordon."

Sincerely,



Steve Coe
Executive Director





POSTGRADUATE CENTER FOR MENTAL HEALTH

124 EAST 28 STREET • N.Y., N.Y. 10016 • 212-576-4102
FAX: 212-576-4198

PERRY W. KAPLAN, M.S.

Director

Quality Assurance/Program Development

July 10, 1995

Mr. Thomas Harmon
State of New York
Commission on Quality of Care for
the Mentally Disabled
99 Washington Avenue
Albany, NY 12210-2895

RE: Draft Report: "In the Matter of Jacob Gordon"

Dear Mr. Harmon:

The Postgraduate Center for Mental Health (PCMH) appreciates this opportunity to comment on the draft report promulgated by the New York State Commission on Quality of Care for the Mentally Disabled (CQC) of its investigation into the death of [redacted] ("Jacob Gordon") on March 29, 1994, entitled "In the Matter of Jacob Gordon."

[redacted] untimely death is a sad reminder that we work within a system that is far from perfect, subject to human frailty and institutional torpor. PCMH believes that the Commission on Quality of Care's draft report presents a careful reconstruction of the series of events leading up to death. This section is clear and concise, and effectively summarizes an obviously extensive interview process. The draft report presents a cogent identification and analysis of many of the factors that led to this tragedy.

Unfortunately, we believe the *Recommendations* section apportions an unreasonable amount of blame to Community Access. It notes, but fails to acknowledge, the seminal role of the psychiatrist in compounding everyday compliance problems by failing to attend even a single case conference or team meeting. This is the major shortcoming of the draft report.

PCMH finds a second serious problem in the draft report's failure to focus on the patchwork of conflicting State laws, regulations and contradictory mandates that are, in fact, the proximate cause of this tragedy. It unrealistically holds Community Access responsible for a system that inexplicably places responsibility for its most difficult and non-compliant clients on its least-experienced and lowest-paid practitioners. In a system where "case management" responsibilities may be shared by several providers and the psychiatrist's responsibility to monitor care is not clearly defined, it is difficult--if not impossible--to assign ultimate responsibility. For this reason, PCMH believes that the CQC's finding of fault with the procedures employed by Community Access is largely unwarranted. Much of their work, particularly the creative and repeated efforts to gain medication compliance are representative of the best efforts of community residence programs to make sense out of a series of laws and regulations that grant consumers autonomy but hold providers responsible for their actions. As long as this situation exists, tragedies like the death of [redacted] are inevitable. The mistakes become

discernible as mistakes only in retrospect. In slightly different circumstances, these same procedures--instituted to encourage and monitor medication compliance--would have been hailed as determined and innovative efforts on his behalf.

Automobile manufacturers are required to provide seatbelts; some states have laws mandating that vehicle occupants wear them. But we do not hold automobile manufacturers responsible for injuries suffered by those who fail to put their seatbelts on. It is truly ironic that the laws of New York State do more to compel individuals to wear seatbelts than to ensure compliance with outpatient treatment. In fact, the current state of regulation is more analogous to enacting legislation that guaranteed individuals the freedom *not* to wear their seatbelts--then held the manufacturers liable for injuries suffered because those same individuals rode beltless.

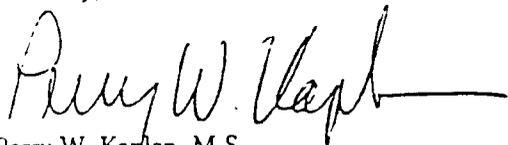
The sad fact is that almost any consumer can so easily fractionate treatment that meaningful monitoring, let alone ensuring compliance, is impossible. Yet that which seems so readily apparent to those of us working with clients each day is glossed over in the Commission's draft report. The Postgraduate Center believes that the psychiatrist should have taken a more active role in medication monitoring and compliance. Taking on a difficult and long-term case like means taking on coordinating responsibilities and cooperating with other treatment providers to a greater-than-usual degree. The draft report notes the psychiatrist's lack of participation but then appears to tacitly approve it. In the *Recommendations* section, the draft report mentions only that the treating physician was not kept informed of non-compliance--rather than exploring the options available to the psychiatrist for becoming informed.

The draft report entitled "In the Matter of Jacob Gordon," therefore, is a well-researched and richly detailed summary of the events that led to the death of . A comprehensive examination of the issues and some appropriate recommendations are marred only by the report's overemphasis on the role of Community Access, its failure to hold the treating psychiatrist responsible for participating fully as a member of treatment team and its difficulty in assessing the ultimate impact of a contradictory patchwork of laws and regulations on the treatment of

Postgraduate Center for Mental Health hopes that you find these comments helpful. Should you have any questions please feel free to call me at 212-576-4102.

Thank you again for the opportunity to participate in the process of developing the final report on this unfortunate incident.

Sincerely,



Perry W. Kaplan, M.S.

Director

Quality Assurance and Program Development

 Visiting Nurse Service OF NEW YORK
HomeCare

A LEADER IN QUALITY HOME HEALTH CARE SINCE 1901

July 13, 1995

Mr. Clarence J. Sundram
Chairman
State of New York
Commission on Quality Care
for the Mentally Disabled
99 Washington Avenue, Suite 1002
Albany, New York 12210-2895

Dear Mr. Sundram:

The Visiting Nurse Service Intensive Case Management Program has reviewed the draft report of the investigation conducted by the Commission on Quality of Care for the Mentally Disabled and its Mental Hygiene Medical Review Board on the circumstances surrounding the death of (Jacob Gordon), an I.C.M. client.

We view Mr. Gordon's untimely death as a tragedy which may have been preventable. The Commission's report is comprehensive and accurately reflects the complexities in attempting to help the severely and persistently mentally ill client maintain autonomy and quality of life in the community. The complexities increase when there is disagreement between service providers and the client over treatment issues such as medication regimes, level of residential supervision, and need for structured participation in day treatment.

The Intensive Case Manager visited Mr. Gordon at least weekly. It should be noted that it often took two or three attempts to see the client at least weekly as the client would often leave his residence or day program before an expected visit from the ICM. Since the client was receiving his medication under supervision of a private psychiatrist and Community Access staff, the ICM focused on developing a relationship of trust and friendship with the client to help improve his self-esteem and decrease his social isolation.

The ICM was aware of Mr. Gordon's level of non-compliance with the Day Treatment Program but not on a daily basis. At times it was difficult to get this information from the client and Day Program staff. The ICM attempted to address the client's resistance to regular attendance by setting up case conferences with the Post Graduate Day Program and through encouraging Mr. Gordon to attend.

In terms of medication compliance, the ICM relied on client reports and reports of Community Access staff. The VNS ICM program agrees with the Commission's finding that the ICM was unaware of the extent of medication non-compliance.

Intensive Case Management

1250 BROADWAY ~ NEW YORK, NY 10001-3701 ~ (212) 290-5222

Mr. Clarence J. Sundram
July 13, 1995

Page 2

The VNS ICM program appreciates the thoroughness and fairness of the Commission's report. The story of Jacob Gordon will teach us a great deal and we are in the process of implementing the Commission's recommendations.

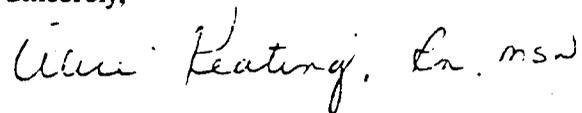
Intensive Case Managers have been instructed to periodically verify the accuracy of verbal reports of medication compliance where non-compliance is an issue and to assure that treating psychiatrists are aware of non-compliance.

ICM Coordinators will participate on a regular basis in the organization of and participation in case conferences for complicated and complex client situations.. These case conferences will occur as the need arises to assess the client's progress, revise service plans as necessary and assure that collaboration and communication occur.

An inservice education program on Clozaril and other psychotropic medications which carry a high risk will be given. Emphasis will be placed on the dangers associated with sporadic non-compliance.

Thank you for your thoughtful recommendations. If I can be of further assistance, please don't hesitate to contact me.

Sincerely,



Alice Keating, RN, MSN
VNS ICM Program Director

AK/fa

The Commission on Quality of Care for the Mentally Disabled is an independent agency responsible for oversight in New York State's mental hygiene system. The Commission also investigates complaints and responds to requests concerning patient/resident care and treatment which cannot be resolved with mental hygiene facilities.

The Commission's statewide toll-free number is for calls from patients/residents of mental hygiene facilities and programs, their families, and other concerned advocates.

Toll-free Number: 1-800-624-4143 (Voice/TDD)



In an effort to reduce the costs of printing, please notify the Commission if you wish your name to be deleted from our mailing list, or if your address has changed. Contact:

Commission Mailroom
NYS Commission on Quality of Care
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401 State Street
Schenectady NY 12305-2397

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