In the Matter of Joan Stalker: A Study of the Need for Vigilant Monitoring of Family Care Homes

A Report

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

and the
Mental Hygiene Medical Review Board

In the Matter of Joan Stalker: A Study of the Need for Vigilant Monitoring of Family Care Homes

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December 1993

NYS COMMISSION
ON QUALITY OF CARE
FOR THE MENTALLY DISABLED

Preface

In New York State, family care is one of the oldest modalities of community-based care for individuals with mental disabilities who are unable to live independently. It is also one of the most special: for a modest monthly stipend, private citizens open their homes and their hearts to one or more disabled persons, promising full inclusion in family life with all its joys, challenges and opportunities for growth.

Historically, family care homes were "sponsored" (ie: certified and supported) by either the Office of Mental Retardation and Developmental Disabilities (OMRDD) or the Office of Mental Health (OMH), whose staff recruited and trained family care providers and visited the homes to ensure compliance with applicable codes, monitor clients' well-being, and offer in-house guidance and training to the care providers.

Recent regulatory changes, however, have permitted not-for-profit agencies with track records of providing services for individuals with developmental disabilities to assume a role in sponsoring family care homes under the oversight of OMRDD.

Nearly 7,000 mentally disabled children and adults live in OMRDD or OMH certified family care homes across the State. And with the continued census run downs in State institutions and an increased emphasis on placement options which most closely mirror the everyday experiences of non-disabled persons, the family care modality is growing, particularly under OMRDD's auspice. Today more than 4,000 individuals reside in OMRDD certified family care homes, an increase of more than 20 percent over the last four years.

This report on the life and death of Joan Stalker[1] illustrates the need for ever-vigilant monitoring of family care homes to ensure that the promise held out by the modality is indeed fulfilled. For Ms. Stalker, it was not.

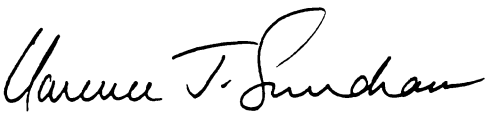
In 1972, Ms. Stalker was placed in a family care home sponsored by OMRDD and designed for four developmentally disabled residents. Unbeknownst to the sponsoring agency, however, the family care provider moved out of the home and at least 12 additional residents, most of whom were mentally ill, were moved in. When this care provider's clandestine activities were finally discovered by the OMRDD after nearly six years, Ms. Stalker and her three developmentally disabled housemates were moved to a new family care home sponsored by a private agency. But soon thereafter, an allegation of abuse in the new home surfaced. Months passed before an investigation into the charge was completed. In the interim, Ms. Stalker died; the autopsy report, and subsequent Commission investigation, indicated her medical needs were neglected and raised the possibility that Ms. Stalker may have been abused. The Commission also found that the residents remaining in the home were subjected to inappropriate disciplinary practices.

While the Commission's investigation prompted the relocation of Ms. Stalker's housemates and the closure of the family care home, it also prompted recommendations to the Office of Mental Retardation and Developmental Disabilities and the Office of Mental Health regarding discharge practices, monitoring family care homes, conducting timely investigations into allegations of abuse/neglect in family care homes and training for sponsoring agencies.

[1] A pseudonym

Both agencies concurred with the Commission's recommendations and copies of their responses are appended to the report.

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



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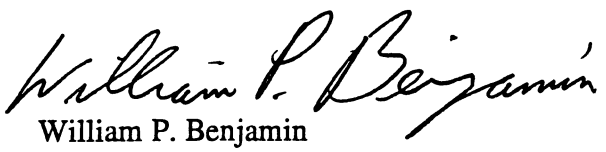

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Introduction

Joan Stalker was a 50 year old mildly retarded woman who lived in a family care home.

In May 1992, the Commission on Quality of Care for the Mentally Disabled received a report of the May 2, 1992 death of Joan Stalker,[1] a 50 year old mildly retarded woman who lived in the family care home[2] of Julia Wayne which was sponsored by the Little Flower Children's Services in Suffolk County, New York.

According to the report, Ms. Stalker had lived in family care for approximately 20 years and was transferred to the Wayne family care home in the summer of 1991, after the home in which she had been residing closed. It was further reported that Ms. Stalker—who had no known life-threatening medical conditions—collapsed suddenly as she was being helped into a van to go from her home to a podiatry appointment. She was rushed to a hospital where she was pronounced dead. The Little Flower Children's Services indicated the death appeared to be due to a massive heart attack and that an autopsy would be conducted.

Due to the sudden and unexpected nature of Ms. Stalker's death, the Commission determined that further review was warranted, and a field investigation was commenced when the autopsy report, received from the Medical Examiner in November 1992, raised the possibility that Ms. Stalker may have been physically abused and neglected.

In May 1992, she died unexpectedly. . .the autopsy suggested that she may have been abused and her needs neglected.

During the investigation, Commission staff reviewed records maintained by the Little Flower Children's Services (Little Flower); the Association for the Help of Retarded Citizens (AHRC), which provided day program services to Ms. Stalker; the Long Island Developmental Disabilities Service Office (LIDDSO), which certifies family care homes on Long Island; private physicians who had examined or treated Ms. Stalker; the community hospital where Ms. Stalker was pronounced dead upon arrival on May 2, 1992; and several psychiatric hospitals which came to the Commission's attention during the investigation.

Commission staff also conducted over twenty interviews with individuals, including the physician in the Medical Examiner's Office who performed the autopsy; Little Flower's family care coordinator and case

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

[2] Family care homes are residences of private citizens who are certified by the State to provide residential services and other care to persons with mental disabilities. Family care homes are usually certified by either the Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities, although there are provisions for the certification of a family care home by more than one agency. In the case of Ms. Stalker, the family care homes in which she resided were certified by the Office of Mental Retardation and Developmental Disabilities and overseen by staff of mental retardation service agencies.

managers who visited the home in which Ms. Stalker lived; nursing and program staff of the AHRC day program; an investigator with the LIDDSO and staff of that agency's family care program; Mrs. Wayne, the family care provider who cared for Ms. Stalker; and two other clients residing in the Wayne family care home. Commission staff also conducted an unannounced visit to the Wayne residence.

This report presents the findings, conclusions and recommendations of the Commission's investigation.

Background

Family Care For The Developmentally Disabled: An Overview

Over 4,000 Developmentally Disabled persons live in family care homes.

Family care is one of the oldest modalities of community-based care for persons with developmental disabilities in New York State, and dates back to 1931. It is also one of the most special: private citizens and families open the doors of their homes to developmentally disabled children and adults who are unable to live independently, but do not require more structured, service- intensive care settings. The family care program is intended to offer stable, surrogate-family living arrangements for these individuals, as well as opportunities and some supervision and training to enhance their abilities and independent living skills. As stated in the Office of Mental Retardation and Developmental Disabilities' regulations, it is expected that family care clients "participate in family and community life on an equal status with other members of the household...and share in that household's pleasures and responsibilities."[3] Today, approximately 4,200 developmentally disabled persons live in family care homes across the State.

It is expected that they participate in family and community life on an equal status with other members of the household and share in the household's pleasures and responsibilities.

The OMRDD's regulations and policies spell out standards and expectations for family care homes, family care providers and other service providers who are involved in, support and monitor the family care program.

Structurally, family care homes must meet all local building codes and conform with additional OMRDD design, space and equipment requirements, which pertain largely to fire/safety and accessibility issues.

In exchange for the clients' monthly SSI benefits, less the personal needs allowance funds,[4] family care providers are expected to, among other things:

- Reside in the same home as the clients and not contract with others to provide permanent care for the residents;
- Ensure that members of the household have an interest in, and acceptance of, the clients and include them in the routine of family life, including meals and recreation;

[3] *Section 687.2 of Title 14 of the Official Compilation of Codes, Rules and Regulations of the State of New York.*

[4] The monthly SSI benefit level for clients in family care is $700.48. Of this, $85 is earmarked for the client's personal needs and is retained by, or on behalf of, the client. The remainder is given to the family care provider as reimbursement for room, board and other services. Family care providers may also receive additional funding to provide special training services for their clients and providers are given an allowance of several hundred dollars a year per client for clothing and other incidentals the client may need.

- Provide for the client's basic needs for a safe, clean and comfortable living environment, personal privacy, appropriate supervision and assistance in daily living, and adequate nutrition and health care;
- Report certain incidents and untoward events involving the clients to appropriate agencies/service providers; and
- Ensure that the number of clients in the home does not exceed its certified capacity. (To promote family living opportunities, the OMRDD has established a policy that no more than four clients can reside in a family care home.)

Among other things, family care providers must provide for the client's basic needs for a safe, clean and comfortable living environment, and report certain incidents and untoward events to appropriate agencies/service providers.

Additionally, family care providers play a role as part of a team of individuals involved in developing and delivering a plan of care to the clients who live in their home. Family care homes are "sponsored" by local mental retardation/developmental disabilities service agencies, either an approved private sector agency or the local Borough/District Developmental Disabilities Service Office (B/DDSO) of the OMRDD. Staff of these sponsoring agencies work with the family care provider, the client and other service providers in developing an overall plan of care addressing the client's medical, social, psychological, vocational, recreational and other needs. Although it is expected that family care clients should, consistent with their plan of care, spend a major portion of their day in formal training, treatment or work programs outside of the home, this does not preclude the development of treatment interventions to be carried out by the family care providers to address some of their clients' needs.

Staff of the sponsoring agency offer family care providers general training in topics including, but not limited to, medication management and administration, first aid, infection control, securing medical assistance, client rights and incident reporting, as well as more specific training in carrying out clients' plans of care. Additionally, staff of the sponsoring agency are expected to visit the family care home once a month to monitor conditions, and to meet with the client at least monthly in either the home or the client's day program (clients must be visited in their day programs at least quarterly). It is also expected that sponsoring agency staff will be available to the family care provider to offer advice and assistance whenever a problem arises.

Staff of the sponsoring agency are expected to visit the family care home once a month to monitor conditions.

In addition to the visits by sponsoring agency staff, family care homes are inspected by B/DDSO staff for certification purposes to determine compliance with applicable standards. Family care homes usually are certified for a two year period.

Findings

Ms. Stalker and Her First Family Care Placement

In 1972, Ms. Stalker was placed in a family care home sponsored by the LIDDSO designed to serve four clients.

Joan Stalker was a mildly retarded, verbal and ambulatory woman who was admitted to Long Island Developmental Center in 1967, when she was 25 years old and her parents could no longer care for her at home. Given her high functioning level, it was believed that Ms. Stalker could benefit from a less restrictive, non-institutional setting and, in 1972, she was placed in the Evers family care home. The home, located in Wyandanch, New York, was sponsored by the Long Island DDSO and had a certified capacity for four clients.

Ms. Stalker lived in the Evers family care home for approximately twenty years. Although the Commission did not thoroughly explore her experiences in this home, LIDDSO and AHRC staff indicated on interview that she did well. Reportedly, Ms. Stalker enjoyed the company of the other three female clients who were placed in the home by the LIDDSO. She was independent in all areas of self care, requiring only verbal reminders to pay a bit more attention to her grooming, and shared in household chores such as sweeping, mopping and bed making. Ms. Stalker evidenced no maladaptive behaviors in the home and, aside from a fibroid uterus and varicose veins, suffered no health problems and required no medications. She spent her days working in the AHRC's sheltered workshop, and her favorite pastime while at home was watching TV.

According to LIDDSO and AHRC staff, Ms. Stalker voiced no complaints about life in the Evers family care home and always appeared well groomed, well nourished and neat, as did the other three family care clients in the home who also attended AHRC day programs.

The Need To Move

In 1991, however, it was discovered that at least 16 clients were living in the home and the family care provider had moved out.

Unbeknownst to LIDDSO and AHRC staff, however, Ms. Stalker and the three other family care clients were not the only individuals residing in the Evers family care home. Beginning in the mid-1980's, as best as the Commission could determine, Ms. Evers began approaching psychiatric centers on Long Island and in New York City, inviting them to discharge psychiatric patients to her home, which they did. She moved out of the home and retained a staff person to work in the home. She also, at some point, acquired at least one other property near her certified family care home, improperly advertised it in the Yellow Pages as an Adult Care Facility (certified by the State Department of Social Services), and began housing psychiatric patients there. Over the years, she would move the residents between her two homes.

By the summer of 1991, in addition to Ms. Stalker and the three other mentally retarded clients, at least twelve other women—mostly former patients of Kings Park and Manhattan Psychiatric Centers—were living in the Evers family care home, which was certified for four individuals. Reportedly, some slept in the basement, and others in cramped, very hot

bedrooms. Based on discharge records secured by the Commission, some had lived in the home since 1985, and while some were discharged directly to the home from their psychiatric centers, others had been discharged from their hospitals to Ms. Evers' other residence, which she advertised as an Adult Care Facility, and then transferred to her family care home.[5]

Although the home operated as a mini-institution for at least six years, LIDDSO staff were unaware of this, despite reported regular visits.

Ms. Evers' clandestine operations came to light in the summer of 1991, following the release of a Commission report on unlicensed boarding homes on Long Island.[6] Upon review of a draft copy of the report, staff of an outpatient psychiatric program became concerned that perhaps Ms. Evers' home was an unlicensed operation. These staff, who had been visiting the home for several years to follow up on some of the patients discharged from psychiatric centers, were unaware that the home was a certified four-bed family care home. They were suspicious, however, that Ms. Evers would never let them visit unannounced, required that either she or her staff person be present when the outpatient staff met with their patients, and never allowed them to tour the house. The outpatient staff were also concerned that so many unrelated people, whom they didn't know and who appeared to be former patients, lived in the home.

The Commission's report, which explained licensing requirements for congregate care facilities and illustrated a case of an unlicensed facility operating illegally, prompted the outpatient program to bring its concerns to the attention of the Office of Mental Health and the Department of Social Services. The LIDDSO was also alerted. Within days, unannounced visits were made by these various agencies which confirmed that at least 16 women, most with psychiatric disabilities, were living in a home certified to house four developmentally disabled individuals.

The LIDDSO immediately removed Ms. Stalker and her three developmentally disabled housemates. Ms. Evers surrendered her operating certificate and moved out of state. Mental health and social services agencies worked to find appropriate placements and services for the other residents who remained in Ms. Evers' home(s).

During interviews, LIDDSO staff indicated that over the years they had regularly visited the Evers family care home, but almost exclusively

[5] The most recent discharges to the Evers family care home occurred in the spring of 1991, when Manhattan Psychiatric Center (MPC) discharged three male patients, one who was HIV positive with a history of assault, to the home. Within a short time, these men were readmitted to MPC after one of them wandered away from the home and, complaining about conditions in the home, requested to be moved. It is unclear whether these men lived in the Evers family care home with Ms. Stalker and the other mentally retarded women, or in Ms. Evers' other home. Manhattan Psychiatric Center staff indicated that the men were discharged to live in Ms. Evers' "Adult Care Facility"; however, the discharge plans prepared by psychiatric center staff list the address of Ms. Evers' family care home as the address to which the men were being discharged.

[6] *In the Matter of the Jacob Home: An Uncertified Adult Home Serving Residents with Mental Illness;* August 1991

on an announced basis. When they visited, they usually sat in the living room and, in the more recent years, never toured the entire house. Staff further indicated that although they always saw people milling about, they did not know that they were living in the residence. Staff explained that at first they thought these individuals were relatives of Ms. Evers; but in time they came to know that Ms. Evers ran "other home(s)" for psychiatric patients, and they assumed that the people milling about were residents from her other nearby home(s) who came by to visit. The staff from the LIDDSO made no attempt to determine who all these other people were, where they came from, or where they lived.

Ms. Stalker and her three mentally retarded roommates were moved to a new family care home.

A New Home

Upon the discovery of Ms. Evers' illicit operations, Ms. Stalker and the other three developmentally disabled women were moved to the Wayne family care home in Dix Hills, a newly certified home sponsored by Little Flower Children's Services in Suffolk County. The Wayne home was chosen as it could accommodate four clients, thus the women—who had lived together for years—would not have to be separated, and it was in a nearby community allowing the women to continue in their day programs.

Once relocated, the women were interviewed by LIDDSO staff to determine whether they had been abused or neglected while in the Evers home; they reported no harsh or unusual treatment, nor any incidents of abuse or neglect by Ms. Evers, her staff, or other residents of the home.

According to day program staff, the transition from the Evers to the Wayne family care home went smoothly, and it appeared that the clients were happy and well cared for in their new home. Little Flower staff—who visited the home monthly, but always on an announced basis—also reported that the women appeared to adjust well to their new placement. Mrs. Wayne, a retired nurse who had worked in a psychiatric center, attended care-planning meetings and brought the clients on family outings; and the clients always appeared well groomed and well nourished, and proudly displayed souvenirs they purchased during their outings.

But within months an allegation of abuse in the new home surfaced.

Signs of Trouble

On the morning of March 19, 1992, seven months after the move, one of the residents of the Wayne family care home, Ms. Kerwin, boarded the bus for her day program. She began crying, and told the driver that Mrs. Wayne had slapped her in the face and pushed her down. Ms. Kerwin had a large red bruise above her right eye and bruises on her right hand and left elbow; her right eye was also somewhat swollen.

Upon arrival at her day program, Ms. Kerwin repeated her story, appeared afraid and upset, and reported that Mrs. Wayne had stated that if she told anyone (about the incident), she (Mrs. Wayne) would get rid of her. Ms. Kerwin requested not to go back to the Wayne residence.

Staff of the day program immediately notified Little Flower of the alleged incident and Little Flower staff arranged for an alternate placement for Ms. Kerwin.

Day program staff also called Mrs. Wayne, who reported nothing had happened that morning and that she didn't need "this kind of aggravation."

While day program staff interviewed the bus driver and Ms. Kerwin, Little Flower staff interviewed Mrs. Wayne, who denied hitting Ms. Kerwin. As the results of these interviews were, in Little Flower's opinion, inconclusive as to whether abuse occurred, the LIDDSO was requested to conduct an investigation.

Nearly four months passed before the findings of the abuse investigation were shared with the agency responsible for the new family care home.

The LIDDSO investigation entailed interviews with Mrs. Wayne, all four residents of her home, the bus driver, and staff of Little Flower and Ms. Kerwin's day program. This investigation revealed inconsistencies in Mrs. Wayne's versions of events as well as evidence which undermined her credibility.

Although Mrs. Wayne initially reported that "nothing had happened," in the course of interviews she changed her story and reported that on the morning of March 19, 1992, she had an argument with Ms. Kerwin, who was standing outside in inclement weather waiting for the bus. According to Mrs. Wayne, when she instructed Ms. Kerwin to come inside to wait for the bus, Ms. Kerwin tripped. Mrs. Wayne, however, stated that Ms. Kerwin did not bang her head and that when she escorted Ms. Kerwin to the bus once it finally arrived, no bruises were evident.

The bus driver, however, reported that when she arrived at the Wayne family care home she had a clear, unobstructed view of the residence and did not see Mrs. Wayne escort Ms. Kerwin to the bus; rather, according to the driver, Ms. Kerwin walked to the bus alone.

Additionally, the bus driver reported that Ms. Kerwin had bruises when she entered the bus.

During the LIDDSO interviews, Ms. Stalker and one other resident of the Wayne family care home denied any knowledge of Mrs. Wayne striking Ms. Kerwin or Ms. Kerwin's injuries. However, a third resident of the home told the LIDDSO investigator that Mrs. Wayne pushed Ms. Kerwin and that Ms. Kerwin fell. This resident also stated that Ms. Kerwin had a red bruise over her eye prior to leaving the house for day program.

In the interim, Ms. Stalker died.

The LIDDSO investigator who completed his report by April 3, 1992 (two weeks after the incident), concluded that Mrs. Wayne did not strike Ms. Kerwin, but had taken "some action" to cause Ms. Kerwin to fall and sustain injuries, and that Mrs. Wayne did not provide treatment of the obvious injuries or notify anyone of the incident.

Little Flower, which conducted no further investigation into Ms. Kerwin's allegation after it was referred to the LIDDSO, was informed of the LIDDSO's findings in late July, four months after the alleged incident and nearly three months after Ms. Stalker's death.

Upon receipt of the LIDDSO's investigation report, Little Flower staff met with Mrs. Wayne to discuss the findings. Mrs. Wayne again denied causing any injury to Ms. Kerwin or having any knowledge that Ms. Kerwin was injured. She claimed that if she had known that Ms.

Kerwin was injured, she would have reported it to Little Flower, as she is expected to do and as she always had done.

Circumstances of Ms. Stalker's Death

On April 22, 1992, about three weeks after the LIDDSO completed its investigation into Ms. Kerwin's allegation, but three months before the findings were shared with Little Flower and discussed with Mrs. Wayne, Ms. Stalker arrived by bus at her sheltered workshop. Ms. Stalker was unable to bear weight on her left leg and staff had to assist her off the bus and transport her to the office using a wheelchair.

In the week or so prior to her death, Ms. Stalker was reportedly ill, and had difficulty walking, but was improving, according to her family care provider.

Mrs. Wayne was contacted by sheltered workshop staff and explained that she believed Ms. Stalker was having trouble with a fallen arch. Mrs. Wayne was advised to take Ms. Stalker home and to arrange for her to be examined by a physician.[7]

The next day, April 23, Mrs. Wayne took Ms. Stalker to a podiatrist who diagnosed a heel spur and plantar fasciitis, an inflammation of the sole of the foot. The podiatrist ordered special shoes for Ms. Stalker and Naprosyn (an anti-inflammatory drug) 500 mg bid.

That afternoon, Mrs. Wayne called Little Flower staff and reported she was having problems with Ms. Stalker. She stated she had taken Ms. Stalker to the podiatrist and that when it was time to leave the office, Ms. Stalker refused to walk, complaining of leg pain, and police had to be called to encourage her to leave the office, which she eventually did. Now at home, Mrs. Wayne reported, Ms. Stalker was refusing to walk anywhere, even to the bathroom.

Little Flower staff immediately went to the Wayne residence and spoke with Ms. Stalker, who was resting in bed. Ms. Stalker told Little Flower staff that she was having some problems with walking, but was feeling better. During the visit, Ms. Stalker was served dinner in bed and, after some discussion, agreed to walk, at least to the bathroom. According to the Little Flower staff member, Ms. Stalker seemed to be in good spirits. At the end of the visit, Mrs. Wayne promised to keep the Little Flower staff member abreast of Ms. Stalker's progress. This was the last time Little Flower staff saw Ms. Stalker.

Two days later, on April 25, Mrs. Wayne called and informed Little Flower staff that she had rented a wheelchair for Ms. Stalker to enable her to get to the bathroom. Two days later, on April 27, Mrs. Wayne called again and advised that Ms. Stalker was doing well but was being held back from her sheltered workshop program, which she last attended on April 22, because the program would not accommodate clients in wheelchairs.

On the morning of May 2, according to a written statement prepared by Mrs. Wayne that day, as Ms. Stalker was being assisted into a van by both Mr. and Mrs. Wayne to attend a follow-up podiatry appointment, she suddenly went limp. Mr. Wayne called 911.

[7] Ms. Stalker was last seen by a physician in February 1992 for her annual physical examination. Aside from having a fibroid uterus and varicose veins, Ms. Stalker was noted to be in good health at that time.

When EMS responded several minutes later, Ms. Stalker was in full cardiac arrest. She was transported to a hospital. Resuscitative efforts en route and in the emergency room were unsuccessful and Ms. Stalker was pronounced dead.

Little Flower staff were advised by Mrs. Wayne that the cause of death was a massive heart attack. However, due to the sudden nature of the death, an autopsy was performed.

Autopsy Raises Questions About Ms. Stalker's Final Days

An autopsy conducted after Ms. Stalker collapsed and died, unexpectedly, revealed she had numerous bruises and a severe bladder infection, suggesting abuse and neglect.

The autopsy performed by staff of the Nassau County Medical Examiner's Office revealed that Ms. Stalker had died as a result of multiple acute pulmonary thromboemboli, bilateral due to deep vein thrombosis of the left leg.

More significantly, the physician who prepared the autopsy report, which was sent to the Commission in November 1992, noted that Ms. Stalker's body had numerous bruises of various sizes and different ages —the oldest being approximately one week old—on her chest, abdomen, shoulder, back and thighs. The physician also noted that, when the body was received, it had an ice pack affixed to a swollen left foot covering a contusion. Additionally, the autopsy report indicated that Ms. Stalker had been suffering from acute hemorrhagic cystitis, an infection of the bladder so severe as to cause bleeding.

Upon receipt of the autopsy report, Commission staff contacted the physician who performed the autopsy. The physician indicated that upon examining the body she entertained the possibility of abuse and spoke with staff of Little Flower and with Mrs. Wayne. Mrs. Wayne, the physician stated, explained the bruises by reporting that in her final week of life, Ms. Stalker had much difficulty walking and frequently fell, bumping into furniture.

The physician, however, remained concerned that Ms. Stalker's medical condition was neglected. The physician reported that Ms. Stalker's cystitis was so extreme that her bladder looked like "raw meat" and it would have produced obvious symptoms of severe pain and bleeding.

Little Flower staff, who were notified of the pathologist's findings of bruises soon after the death occurred, did not conduct an investigation, despite the fact that Mrs. Wayne—who attributed the bruises to Ms. Stalker's frequent falls during her last week of life—never reported the falls or the bruises to Little Flower.

Following interviews with the pathologist, Commission staff interviewed Mrs. Wayne and the two clients who remained in her home. Commission staff also alerted the LIDDSO to the autopsy findings, and an investigator from that agency was assigned to the case.

In the various interviews conducted, Mrs. Wayne gave conflicting statements. Whereas on one occasion she claimed that Ms. Stalker fell numerous times in her last week of life, she later claimed that Ms. Stalker fell only once—on the day of the April 23, 1992 podiatrist appointment

—and was bed-bound for the next nine days, requiring diapers and bed baths, as she would not even walk to the bathroom. Mrs. Wayne told Commission investigators that she believed Ms. Stalker's bruises were the result of the fall which occurred on the day of the April 23 podiatrist visit. However, she told the LIDDSO investigator that she was unaware of bruises on Ms. Stalker's body, although she reported having to give Ms. Stalker bed baths and having to change her diapers.

In ensuing interviews, the family care provider offered inconsistent and incredulous accounts of Ms. Stalker's final days and condition.

Concerning Ms. Stalker's cystitis, Mrs. Wayne, a registered nurse, indicated Ms. Stalker never complained of abdominal discomfort, and although she (Mrs. Wayne) noted blood in Ms. Stalker's diapers, she believed Ms. Stalker was having her period. The Commission investigators, also nurses, found this incredulous and noted that clinical records indicated Ms. Stalker voiced complaints of abdominal cramps during her menses.

The other two residents of Mrs. Wayne's home denied seeing Ms. Stalker abused and indicated that, during her final days, Ms. Stalker spent most of her time in bed in her room. Interviewed with the assistance of their day program staff, however, the clients disclosed that in the Wayne home they were forced to sit on a floor in a corner facing the wall when they "were bad." This disclosure shocked the staff of the day programs, who also noted changes in the clients' demeanor when questions were posed about disciplinary practices in the home; day program staff sensed the clients were afraid and holding back the full story.

Other clients in the home confided to the Commisson they had been subjected to degrading discipline.

While it could not be determined with certainty whether Ms. Stalker was physically abused in the Wayne home or whether she fell once or multiple times, it was clear that Mrs. Wayne failed to notify Little Flower of significant events in the last week of Ms. Stalker's life, including her continuing difficulty ambulating, fall(s), bruises, bedridden status, reliance on diapers due to incontinence, bleeding, refusals to walk, and her need for bed baths. It also became evident during the investigation that Mrs. Wayne employed inappropriate disciplinary practices in her home to punish or control resident behavior.

In December 1992, the LIDDSO, which confirmed the Commission investigators' findings, relocated the two remaining clients out of the Wayne home, as it was believed that their continued residency in the home posed a risk to their health and welfare.

Conclusion and Recommendations

Family care offers the promise of what we all most cherish: inclusion in the fabric of society. The case of Joan Stalker, however, is a study in just how fragile that promise is.

As one of the oldest forms of community-based care for persons with developmental disabilities in New York State, the family care modality —in its intent and design—offers the promise of what we all most cherish: inclusion in the fabric of society. Through the delicate weaving of a natural family willing to open the doors of its home to a disabled individual, and the assistance of professionals charged with providing and assuring services appropriate to the disabled person's needs, developmentally disabled individuals are afforded the opportunity to participate in the joys and responsibilities of family life and engage in out-of-home programs and activities. Family care offers the promise of expanding the horizons for growth and development of developmentally disabled persons through the nurturance of surrogate family members, meeting new friends, and encountering the challenges posed by everyday family life and community living.

The case of Joan Stalker, however, is a study in just how fragile that promise is.

For years, Ms. Stalker and three other developmentally disabled women lived in a family care home certified for four individuals. Far from offering a family-like experience, however, the home more closely resembled a mini-institution, and a poor one at that. The family care provider had moved out of the home; at least 12 additional women, most former psychiatric inpatients, were moved in and, for a brief period, it appears that three male patients from a psychiatric center may have been housed in the home. Contrary to State regulations, the family care provider hired staff to supervise what amounted to a boarding house for former psychiatric patients, while she resided elsewhere.

In the earlier years, responsible staff failed to detect the home was an overcrowded "mini-institution."

Staff from the LIDDSO, which sponsored this family care home, reported that they made routine visits to the home. During these announced visits, however, it is clear that they never toured all areas of the house. And even when they noticed many obviously disabled people milling about the house, LIDDSO staff never inquired as to who these individuals were, where they came from, or where they lived.

When conditions in the home were finally uncovered several years later, Ms. Stalker and her three peers were offered anew the promise of family life and community living, and were placed in the Wayne family care home.

Within months, though, there was a warning that life in the Wayne home was not what one would want for a family member; one of the clients reported that Mrs. Wayne had slapped her, pushed her down, and threatened to "get rid of" her if she told anyone. Bruised and afraid to return to the home, the client requested placement elsewhere; and she was the same day.

Staff of the sponsoring agency, Little Flower, requested the LIDDSO to conduct an investigation into the client's charges. Although Mrs. Wayne denied harming the client and denied observing her injuries, conflicts in her testimony and statements of witnesses raised questions

about her credibility. Within two weeks, the LIDDSO investigator concluded Mrs. Wayne had caused the client to fall and sustain injuries and that she failed to report either the fall or the injuries to Little Flower as required.

Allegations or suspicions of abuse or neglect were not aggressively pursued.

The investigation report, however, was not shared with Little Flower or discussed with Mrs. Wayne for nearly three months. In the interim, Ms. Stalker died. Upon autopsy, it was discovered that Ms. Stalker had numerous bruises of various sizes and ages on her body, and that she had been suffering from a painful, bleeding infection of the bladder. Although notified of the bruises by the Medical Examiner's Office, Little Flower neither conducted an investigation, nor notified the LIDDSO to which the other client's allegation of abuse had been referred.

During investigations sparked by the Commission upon receipt of the autopsy report, Mrs. Wayne gave conflicting statements about the origin of the bruises on Ms. Stalker's body; her rationale for not following up on Ms. Stalker's bleeding bladder defied belief; and it was clear that she had not notified Little Flower of Ms. Stalker's troubling medical conditions during her last week of life. Asking the two remaining residents of the home the simple question "What happens if you are bad at home?" prompted their disclosure that they were forced to sit in a corner on the floor facing a wall. Subsequently, the home was closed and the two clients moved to a new family care home, with a new promise.

The experiences of Ms. Stalker and her three friends are not usual. Over the years, the Commission has encountered many family care providers who fulfill the promise of this modality by opening not just their doors, but their hearts to disabled persons, offering them the same care, respect and opportunities for growth as are afforded other family members. However, the Commission has also encountered situations where, as in Ms. Stalker's case, the promise embodied in the family care model has been broken.

Recommendations

The family care program on Long Island requires scrutiny.

The uniqueness of this modality—with private citizens providing 24 hour, seven day a week care in their private residences—requires that sponsoring and certifying agencies must be ever-vigilant in their monitoring and support duties to ensure that the promise held out to developmentally disabled persons is not chipped, cracked and eventually shattered.

Toward that end, the Commission recommends that the Office of Mental Retardation and Developmental Disabilities should review the operations of the family care program on Long Island, and the roles and effectiveness of the sponsoring agencies in that region of the State. The Commission is extremely troubled that at least 16 individuals, many former patients of psychiatric centers, were living in a family care home certified for four developmentally disabled persons and that this situation went undetected by LIDDSO staff until 1991, despite the fact that some of the patients had been discharged to the home

as early as 1985. It is also disconcerting that when the clients were moved to a family care home and an allegation of abuse was raised, Little Flower essentially suspended its investigation while awaiting the results of an LIDDSO investigation. That investigation took nearly four months to be shared with Little Flower. In the interim, Ms. Stalker, bruised and suffering from an untreated medical condition, died. Furthermore, Little Flower, which was informed of the bruises found on Ms. Stalker's body at the time of the autopsy, did not conduct an investigation, nor did it refer the matter to the LIDDSO.

This case suggests the need for reaffirming expectations and training statewide.

The Commission also recommends that, on a statewide basis, the Office of Mental Retardation and Developmental Disabilities should:

- Reiterate to all sponsoring agencies their duty to conduct timely and thorough investigations into allegations of abuse in family care homes. In cases where the sponsoring agency requests an investigation by the local B/DDSO, the completion of the investigation should be prompt and the sponsoring agency should maintain regular contact with the investigator to ensure that any findings signaling the need for protective or remedial action trigger such promptly.
- Ensure that sponsoring agencies periodically visit family care homes on an unannounced basis.
- Ensure that when sponsoring agency staff visit family care homes they periodically tour the entire house to monitor for structural modifications or changes in the household's composition which may raise questions or concerns.
- Require that when a family care client is absent from day program for a prolonged period of time due to illness, sponsoring agency staff visit the home to monitor the client's well-being and determine whether the family care provider is rendering reasonable care or requires any additional assistance.
- Advise sponsoring agency staff to periodically discuss and explore disciplinary practices in family care homes when they meet with their clients.

Additionally, the Office of Mental Retardation and Developmental Disabilities should disseminate this report to all agencies sponsoring family care homes, and require that staff of the family care programs discuss the issues raised in the report with an eye toward determining whether they have adequate safeguards to reduce the likelihood of similar situations occurring in their program.

The Commission's investigation also raised serious concerns about the discharge practices of State Psychiatric Centers. As indicated in the report, certain State Psychiatric Centers discharged patients to an unscrupulous woman who misrepresented her operations. These centers apparently failed to conduct even minimal background checks—checks which would have revealed that one of her homes was a family care home certified for only four developmentally disabled clients and that her other home was an unlicensed adult care facility.

There are lessons to be learned by the Office of Mental Health.

The Office of Mental Health should review the discharge practices of these facilities which have been cited in previous Commission reports.[8]

Additionally, as the Office of Mental Health also certifies and sponsors family care homes serving more than 2,400 mentally ill individuals, the Office should consider disseminating the Commission's report on Ms. Stalker to its family care units as a teaching tool, and for their reflection on the question: "Could this happen in our program?"

[8] *In the Matter of the Jacob Home: An Uncertified Adult Home Serving Residents with Mental Illness,* August 1991; *Life and Death at New Queen Esther Home for Adults,* June 1993; *Falling Through the Safety Net: "Community Living" in Adult Homes for Patients Discharged From Psychiatric Hospitals,* August 1993.

Appendix

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 12229-0C

ELIN M. HOWE
Commissioner

THOMAS A. MAI
Executive Deputy Commissio:

August 16, 1993

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

Dear Chairman Sundram:

This is in response to the Commission's recently issued draft report entitled In the Matter of Joan Stalker: A Study in the Need For Vigilant Monitoring of Family Care Homes. Your willingness to share this confidential draft report in order to obtain OMRDD's input and comments is appreciated. As the Commissioner of the state agency responsible for certifying family care homes, it is very troubling to review the tragic circumstances which culminated in the death of Ms. Stalker.

With respect to the specific recommendations made in the report, each will be addressed in the corresponding order of their appearance in the report.

"The Commission recommends that the Office of Mental Retardation and Developmental Disabilities should review the operations of the family care program on Long Island, and the roles and effectiveness of the sponsoring agencies in that region of the State."

Since the discovery in the summer, 1991, that several former patients of psychiatric centers were living in a family care home certified for four developmentally disabled persons, significant efforts in the monitoring and oversight of family care providers has been undertaken by the Long Island DDSO case managers. An August 1, 1991 letter to state operated family care providers from the Long Island DDSO Director of Family Care case management services clearly provided the framework and basis for the increased vigilance which has occurred.

Despite such positive efforts by the Long Island DDSO, I will request that a review of the operations of the family care program on Long Island, with particular focus

on the roles and effectiveness of the sponsoring agencies, be undertaken. This review will be conducted during the next few months and a summary report of the findings will be shared with the Commission by the end of the year.

The following Commission recommendations made to OMRDD have statewide applicability:

"Reiterate to all sponsoring agencies their duty to conduct timely and thorough investigations into allegations of abuse in family care homes. In cases where the sponsoring agency requests an investigation by the local B/DDSO, the completion of the investigation should be prompt and the sponsoring agency should maintain regular contact with the investigator to ensure that any findings signaling the need for protective or remedial action receive such promptly."

This is a common sense approach to information sharing which occurs in our regular activities on a daily basis. The Commission's report regarding Joan Stalker provides a clear and obvious example of the need to share such information. Please be assured that all family care sponsoring agencies and local B/DDSOs will be reminded of this fact.

"Ensure that sponsoring agencies periodically visit family care homes on an unannounced basis."

"Ensure that when sponsoring agency staff visit family care homes they periodically tour the entire house to monitor for structural modifications or changes in the household's composition which may raise questions or concerns."

"Require that when a family care client is absent from day program for a prolonged period of time due to illness, sponsoring agency staff visit the home to monitory the client's well-being and determine whether the family care provider is rendering reasonable care of requires any additional assistance."

"Advise sponsoring agency staff to periodically discuss and explore disciplinary practices in family care homes when they meet with their clients."

OMRDD has been continuously reviewing, revising and updating, as appropriate, our policies and procedures regarding the growing family care program. This effort has been accomplished through the cooperative efforts of our Family Care Advisory Council, which is comprised of individuals representing all sections of the family care program.

The Commission's final Joan Stalker report will be shared with members of the Advisory Council. Since Little Flower is represented on the Advisory Committee and they have already committed to implementing these recommendations, (in a June 24, 1993 letter to Mr. Thomas Harmon), I am confident that the full advisory council will concur with their actions. Upon the anticipated approval by the Advisory Committee, the recommendations will be appropriately incorporated into the Family Care Policies and Procedures.

"Additionally, the Office of Mental Retardation and Developmental Disabilities disseminate this report to all agencies sponsoring family care homes, and require that staff of the family care programs discuss the issues raised in the report with an eye toward determining whether they have adequate safeguards to reduce the likelihood of similar situations occurring in their program."

I wholeheartedly concur that a review of history in many instances can be our best teacher. By sharing the Commission's final report and raising everyone's awareness of the need to develop and maintain appropriate safeguards for the individuals we service we will hopefully eliminate this type of tragedy from occurring again.

The statewide dissemination to all sponsoring agencies of the Commission's final report will also be discussed with the Advisory Council. I would like the Council to have an opportunity to provide their input in the approach we take in disseminating the report.

The promise offered through the family care modality of community based living for persons with developmental disabilities is realized each and every day for approximately 4,200 individuals in New York State. An unfortunate and isolated case, as seen in the Joan Stalker report, should serve to revitalize our collective efforts at ensuring that the promise is fulfilled. OMRDD is committed to that goal and will continue to effectuate appropriate modifications and revisions in our oversight responsibilities to achieve that mission.

Thank you for the opportunity to provide comments to the draft report. Should there be any questions regarding this, please do not hesitate to contact me.

Sincerely,

Elin M. Howe

Elin M. Howe
Commissioner

EMH/NC
cc: Mr. Catchpole
Mr. Robidoux

NEW YORK STATE
OFFICE OF MENTAL HEALTH
44 Holland Avenue, Albany, New York 12229

RICHARD C. SURLES, Ph.D., Commissioner

August 19, 1993

Clarence Sundram, Chairman
Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue - Suite 1002
Albany, NY 12210

Dear Mr. Sundram:

This letter is in response to the findings and recommendations contained in the Commission's confidential draft report: In the Matter of Joan Stalker: A Study in the Need for Vigilant Monitoring of Family Care Homes. Although the subject of the report is the care provided to a developmentally disabled individual living in a family care home certified by the Office of Mental Retardation and Developmental Disabilities, it also raises concerns regarding the discharge practices of Manhattan Psychiatric Center and Kings Park Psychiatric Center.

As described in the Commission's report, it was discovered in 1991 that a group of former psychiatric center patients from these two facilities had been discharged to a "woman who misrepresented her operation as appropriately licensed." Details of similar problems identified in unlicensed homes such as this one were clearly described in the Commission's 1991 report: In the Matter of Jacob Home: An Uncertified Adult Home Serving Residents with Mental Illness. The findings and recommendations of that report led to a number of changes in the discharge practices of Kings Park and other psychiatric centers in the Long Island region including:

- Development of a set of Case Management Standards that are now used by the Long Island Regional Office to monitor case management programs.

- Designation of a Discharge Planning Unit at Kings Park Psychiatric Center which is distinct from the Social Work Department. This unit is responsible for monitoring discharges and compliance with Mental Hygiene law and good clinical practice.

- Development of a centralized and automated Suffolk County clearinghouse for housing which maintains an updated listing of licensed, unlicensed and acceptable housing.

Within the New York City region, no patients from Manhattan P.C. have been placed in residences on Long Island since the Spring of 1991. In addition, Manhattan P.C. is working closely with its discharge planning staff to ensure that patients are referred only to licensed facilities and that unscheduled visits are conducted for several weeks following discharge to ensure the residents' well being.

In light of the Commission's current report, the director of the New York City Regional Office has issued a directive (attached) to psychiatric centers within the region regarding placement to family care settings. It reminds them of their responsibility to determine that any family care home to which a patient is discharged must be appropriately licensed and currently in compliance with regulatory standards. It also reminds them of their responsibility to conduct sufficiently frequent visits (including unannounced visits) to assure adequate oversight.

As you can see, there have been significant efforts to improve the discharge planning process within the Long Island and New York City regions and ensure that patients are not placed in any type of unlicensed, unmonitored setting. As suggested by the Commission, the current report can indeed serve as a valuable "teaching tool" to further these efforts. It will be disseminated to key staff within OMH for their review.

Thank you for the opportunity to comment on the confidential draft report. If you have any questions regarding this response, please feel free to contact Dr. Sandra Forquer, Deputy Commissioner for Quality Assurance and Information Systems.

Sincerely,

Richard C. Surles, Ph.D.
Commissioner

cc: Sandra Forquer, Ph.D.

OFFICE OF MENTAL HEALTH
RICHARD C. SURLES, Ph.D., Commissioner

NEW YORK CITY REGIONAL OFFIC
275 Seventh Avenue - 16th Flo
New York, New York 10001-6C
(212) 627-62

ROBERT T. HETTENBACH, Regional Direct

MEMORANDUM

TO: Michael Ford, M.D.
Patricia Lambert
Marlene Lopez
Lucy Sarkis, M.D.
Charlotte Seltzer

FROM: Robert T. Hettenbach *Robert T. Hettenbach*

DATE: August 9, 1993

SUBJ: Placement to Family Care Settings

As you may know, the Commission on Quality of Care for the Mentally Disabled has recently concluded a review of Family Care Homes.

While the focus of the report is an individual with mental retardation who was placed in settings outside of this region, the issues identified are of relevance to any facility that utilizes this level of care for discharged patients. Consequently, I am writing to alert you to two important considerations.

First, staff who are responsible for discharge planning should be reminded that prior to placement in a Family Care setting, there must be a determination that the home is duly licensed (if applicable) and is currently in compliance with regulatory standards. Inquiries and findings about the regulatory status of a home that is being considered for placement should be clearly documented in the patient's record.

Secondly, once patients are discharged into a Family Care home, it is our expectation that facility staff will visit with a frequency that assures adequate oversight, consistent with a patient's need and capacity for self direction. Some visits should be conducted without notice and it should be made clear to Family Care providers that their cooperation with unannounced visits is both expected and a condition of placement to their home.

If Psychiatric Center staff encounter serious deficiencies, it is their responsibility to either relocate vulnerable individuals or work with the provider toward rapid resolution of the problem. If needed, staff should consult with Michael Chambers on enforcement of certification standards.

Please be certain that all staff who engage in discharge planning are aware of the above.

Gary W. Masline (W) 518-473-7538
(H) 518-427-1718

Embargoed until A.M. Tuesday, December 14, 1993

Death Reveals Flaws in Family Care Home Monitoring

The death of a 50 year-old mentally retarded woman, who lived in a Suffolk County "family care" home, underscores the need for proper monitoring and support from agencies which sponsor and certify individuals who undertake to serve mentally disabled persons. A state "watchdog" agency investigation resulted in the home's closure, and cited state and local agencies for ineffective monitoring of the home and failure to safeguard its residents while abuse allegations were under investigation. State agencies also were cited in the report for not detecting an illegal and overcrowded family care home in Suffolk County, where the deceased previously lived, and for inappropriate discharges from state psychiatric centers to the home.

The State Commission on Quality of Care for the Mentally Disabled, an independent agency responsible for oversight in the mental hygiene system, and its Mental Hygiene Medical Review Board today released a report on the May 1992 death, entitled **"In the Matter of Joan Stalker[1]: A Study on the Need for Vigilant Monitoring of Family Care Homes."** The Commission investigation found:

- autopsy findings revealed severe bruising and a raging bladder infection, suggesting abuse and neglect by the operator of the family care home where the woman died.
- despite earlier warnings of possible abuse at the home, the local sponsoring agency failed to ensure the safety of its four residents.
- state psychiatric centers improperly discharged patients to a family care home where the deceased previously lived, which was only certified for mentally retarded individuals. That home's eventual closure resulted in the deceased's move to a second home where she died. And
- the state agency responsible for oversight of Long Island family care homes allowed the first family care home to operate without detecting the grossly overcrowded conditions.

According to the Commission report, in 1972 Ms. Stalker had been placed by Long Island Developmental Center in a Suffolk County family care home certified for four clients by the State Office of Mental Retardation and Developmental Disabilities (OMRDD). For many years, Ms. Stalker thrived in the home but, in the mid 1980's, the home operator approached psychiatric centers on Long Island and in New York City which then improperly discharged at least 12 psychiatric patients to her home. The resulting overcrowding and the home operator's subsequent move out of the house violated OMRDD regulations and destroyed the intended "family-like" atmosphere, transforming the home into what the commission called "a mini-institution." The four mentally retarded women and twelve other women, mostly former patients of Kings Park and Manhattan Psychiatric Centers, endured cramped, hot bedrooms, and some reportedly were forced to sleep in the home's basement.

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[1]A Pseudonym.

(more)

The home operator's clandestine operation went undetected for nearly six years by Long Island District Developmental Disabilities Services Office (LIDDSO), the OMRDD agency responsible for recruiting and training home operators, which had responsibility for visiting and inspecting home conditions to ensure client well-being. LIDDSO rarely completed full inspections or conducted unannounced visits at the home. But in 1991, when the Commission released a report on unlicensed boarding homes elsewhere on Long Island,[2] outpatient mental health program staff reported the family care home's overcrowding, and it was closed. The four mentally retarded residents including Ms. Stalker were transferred to a newly-certified family care home in Suffolk County sponsored by Little Flower Children's Services (Little Flower), a private agency approved by OMRDD.

However, seven months after the move a home resident alleged to staff at her Association For the Help of Retarded Citizens (AHRC) day program that the family care home operator had slapped and pushed her to the floor, and threatened to "get rid of her" if she told. After an inconclusive interview of the home operator, Little Flower requested an investigation by LIDDSO, the OMRDD oversight agency. Little Flower then ceased following the investigation and though an LIDDSO investigator completed a report 2 weeks after the incident, four months passed before the findings were reported to Little Flower, concluding that the home operator had caused the resident's injuries.

In the interim, Ms. Stalker died on May 2, 1992, after collapsing on the way to a podiatry appointment. The autopsy report and subsequent Commission investigation of the death indicated her medical needs had been neglected, that she too may have been a victim of abuse and neglect by the family care operator, and that home residents regularly had been subjected to inappropriate punishment. The autopsy found: many bruises of varying size and age on Ms. Stalker's chest, abdomen, shoulder, back and thighs; her bladder resembled "raw meat" from an infection so severe it caused painful bleeding; and a contusion on her swollen left foot.

When the home operator told the autopsy physician Ms. Stalker's bruises were caused by falls, Little Flower neither investigated nor even notified LIDDSO, despite the operator's failure to report to Little Flower as required the alleged falls and bruises, Ms. Stalker's difficulty walking, her bedridden status the last days of her life, her need for diapers and bed baths due to incontinence, or the bleeding. The home operator, a nurse, denied awareness of the bladder condition to Commission investigators, despite giving Ms. Stalker bed baths, seeing blood in her diapers, and Ms. Stalker's complaint of abdominal pain. Other home residents reported to Commission investigators that they were forced to sit on the floor in a corner facing the wall as a form of discipline.

The Commission's investigation resulted in closure of this family care home by OMRDD, and OMRDD and the State Office of Mental Health (OMH) have agreed to use the report as a training vehicle for family care home-sponsoring agencies throughout the state to prevent similar tragedies. OMRDD also agreed to review its family care program operations on Long Island. The report recommended to OMH that Commission findings concerning improper discharge practices by State Psychiatric Centers to uncertified facilities be addressed, as the Commission has recommended in previous reports.[3] A recent OMH directive reminded psychiatric centers in the New York City area of their responsibility to determine that family care homes to which patients are discharged are properly licensed and in compliance with regulations, and directs them to conduct unannounced visits to ensure compliance.

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2 *In The Matter of the Jacob Home: An Uncertified Adult Home Serving Residents with Mental Illness;* August 1991.

3 *In the Matter of the Jacob Home: An Uncertified Adult Home Serving Residents with Mental Illness,* August 1991; *Life and Death at New Queen Esther Home for Adults,* June 1993; *Falling Through the Safety Net: "Community Living" in Adult Homes For Patients Discharged From Psychiatric Hospitals,* August 1993.

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

MEMORANDUM

FROM: Clarence J. Sundram

DATE: December 8, 1993

SUBJECT: **In the Matter of Joan Stalker: A Study of the Need for Vigilant Monitoring of Family Care Homes**

Enclosed is the report of the Commission and Mental Hygiene Medical Review Board on the investigation of the death of Joan Stalker (a pseudonym), a resident of a family care home in Suffolk County. Family care is intended to provide surrogate-family living for individuals with mental disabilities who are unable to live independently, and who would benefit from supervision and training in a family setting. Over 4,000 individuals reside in OMRDD-certified family care homes, an increase of more than 20 percent during the last four years. Our investigation revealed the need for more aggressive and comprehensive monitoring by OMRDD to insure the safety and well-being of individuals entrusted to the care of family care homes.

The Commission investigation of the death indicated Ms. Stalker's medical needs were neglected and that there was evidence of abuse and neglect by the home operator. She had many bruises, a severely infected bladder resembling "raw meat" and accompanied by painful bleeding, and a contusion on her foot. The operator failed to report Ms. Stalker's falls and bruises, difficulty walking, bedridden status the last days of her life, her need for diapers and bed baths due to incontinence, or the bleeding, to the agency sponsoring the home. Even when the agency learned of the autopsy results, it failed to investigate or to notify OMRDD. In the course of the investigation, CQC learned of other residents of the home who were also abused.

The Commission's investigation resulted in closure of the home by OMRDD. OMRDD and OMH have agreed to use the report in training of family care home-sponsoring agencies, and OMRDD is reviewing family care program operations on Long Island. The Commission's report recommends OMRDD ensure its sponsoring agencies swiftly and thoroughly investigate abuse allegations and take measures to protect home residents.

We also recommend that OMH address Commission findings concerning improper discharge practices by psychiatric centers to uncertified facilities, as the

Commission has urged in previous reports[1]. In the course of this investigation, the Commission learned that psychiatric facilities in New York City and Long Island had discharged 12 patients into another family care home certified by OMRDD for 4 residents, in which Ms. Stalker had previously resided. A recent OMH directive reminded psychiatric centers in the New York City area of their legal responsibility to determine that family care homes to which patients are discharged are properly licensed and in compliance with regulations.

The findings, conclusions and recommendations of the Commission report reflect the unanimous opinion of the members of the Commission. A draft of this report was reviewed by OMRDD and OMH. Their responses are appended to the report.

This report is being filed in accordance with Article 6 of the Public Officers Law and is considered a public document.

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[1]In the Matter of the Jacob Home: An Uncertified Adult Home Serving Residents with Mental Illness, August 1991; Life and Death at New Queen Esther Home for Adults, June 1993; Falling Trough the Safety Net: "Community Living" in Adult Homes for Patients Discharged from Psychiatric Hospitals, August 1993.

The Commission report further recommended OMRDD ensure that its sponsoring agencies:

- swiftly and thoroughly investigate abuse allegations, while maintaining contact to protect home clients.
- ensure regular, unannounced and comprehensive visits to homes.
- require visits to ensure that clients who are absent from their day program due to prolonged illness have their needs met. And
- advise sponsoring agencies to discuss discipline at homes with the clients.

Today, over 4,000 individuals reside in OMRDD-certified family care homes across the state, an increase of more than 20 percent during the last four years. As reductions in the populations at state institutions increase, the need grows for placements in the community which, with some support services, can approximate the everyday life of non-disabled persons. In exchange for a modest fee to the home operators, family care clients participate in family and community life and share in household responsibilities. Family care is intended to provide stable, surrogate-family living arrangements for such children and adults who are unable to live independently, but who don't need more structured care and services, and who would benefit from supervision and training in a family setting to increase their abilities and independent living skills. The Commission is required by the Mental Hygiene Law to review deaths of mental hygiene system program clients to determine whether circumstances surrounding a death suggest deficiencies in care.

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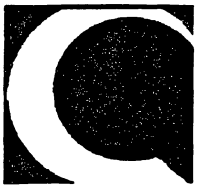
The Commission on Quality of Care for the Mentally Disabled is an independent agency responsible for oversight in New York State's mental hygiene system. The Commission also investigates complaints and responds to requests concerning patient/resident care and treatment which cannot be resolved with mental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



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