

In the Matter of Francis Helms

A REPORT

BY THE NEW YORK STATE
 COMMISSION ON
QUALITY OF CARE
FOR THE MENTALLY DISABLED
AND THE MENTAL HYGIENE
MEDICAL REVIEW BOARD

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Preface

The story of Francis Helms'* final years and eventual death is a tragic one. The tragedy is that it is a story which never should have had to have been told. Yet, that is why it needs telling.

For the last eight years of his life, Francis Helms--a middle aged, profoundly retarded man--was kept locked in a small, filthy, barren room in the home of a private caretaker. He spent his days semi-nude, sitting on a commode, with little or no stimulation, or opportunity to exercise the skills he once possessed or to learn new ones. He went on only one trip: in June 1987 he was taken by ambulance to a community hospital. Suffering from malnutrition, dehydration and decubitus ulcers emitting a gangrenous odor and exposing muscle tissue and bone, he was admitted. However, he died of bilateral bronchopneumonia five days later.

Over the course of the last eight years of his life, Mr. Helms' situation was not a secret. His state of deprivation and incarceration was known, almost immediately after his 1979 placement in the private home, to agencies sharing a mission of providing protective services to vulnerable persons: The Suffolk County Department of Social Services' Protective Service for Adults program (PSA) and the Long Island Developmental Disabilities Service Office (LIDDSO).

Mr. Helms' conservators, appointed by the State of Connecticut, as well as a representative of the firm administering

his trust, were also aware of concerns about Mr. Helms' situation as early as 1979. Yet, apparently waiting for the PSA and LIDDSO to take action, these custodians of Mr. Helms' estate and well being took little action on their own to ensure that his needs and comfort were well met.

This report chronicles the actions and inactions of various parties responsible for ensuring Mr. Helms' protection. While recognizing the role of Mr. Helms' conservators and other private persons involved in Mr. Helms' life--including a private physician, whose conduct the Commission reported to the Department of Health--the report focuses primarily on the responsiveness of New York State's protective service network, which was designed to ensure the well being of vulnerable persons who have no one willing or able to care for them. Administered by the State Department of Social Services through its local districts, the Protective Services for Adults program is recognized as requiring the aid and assistance of a constellation of public and private human service agencies to achieve its intended goal (Social Services Law §473).

The case of Francis Helms demonstrates how unclear expectations, poor service planning and interagency coordination and cooperation can erode the State's protective mission with tragic results. For years, staff of the local Department of Social Services visited Mr.

*A pseudonym for the deceased.



Helms and dutifully documented in his case record observations of his deprivation and isolation. Periodically, beginning in 1979, requests for assistance were issued by the local DSS to the LIDDSO with little positive reaction. In fact, it took the LIDDSO eight months to visit and assess Mr. Helms following a June 1986 local DSS request for an "immediate" evaluation. And by the time the LIDDSO determined that Mr. Helms should be evaluated for a nursing home placement and arranged for the evaluation, Mr. Helms was admitted to the hospital where he died.

The sobering reality of the Francis Helms case is not just that private individuals failed to protect his interests, but that the safety net of protective services designed by the State to catch such failures also failed to achieve its objective.

To prevent the recurrence of similar tragedies, the Suffolk County Department of Social Services and the LIDDSO, subsequent to Mr. Helms death, developed a memorandum of understanding delineating their joint and respective responsibilities for the protection of vulnerable developmentally disabled adults residing in the community. Reportedly, this agreement has led to prompt and successful joint intervention on behalf of "at-risk" clients in Suffolk County.

However, with over 90,000 substantially developmentally disabled persons residing at home or in unlicensed settings

across the State, the Commission believes that there exists a need for broader action to ensure appropriate interagency protective action on their behalf when the need arises.

The recommendations offered by the Commission are intended to promote clarity of expectations between agencies sharing a protective mission and a more responsive protective service system statewide. In response to a draft copy of this report, the Department of Social Services and the Office of Mental Retardation and Developmental Disabilities substantially concurred with the Commission's findings and recommendations (see Appendix B).

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CHAPTER I

Introduction

On the evening of June 23, 1987, Francis Helms* -- a 60-year-old profoundly retarded man -- was taken by ambulance from the home of his private caretaker to Community Hospital of Western Suffolk (CHOWS). According to hospital records, Mr. Helms arrived at the emergency room in an emaciated, moribund state. He was filthy and his hair was matted with feces. Preliminary medical assessments revealed that Mr. Helms was dehydrated, malnourished and suffering from multiple large decubitus ulcers in various stages of development on his upper torso; one ulcer was so severe that it emitted a gangrenous foul odor and exposed muscle tissue and bone. Upon admission, one of Mr. Helms' sisters, who with another sister served as Mr. Helms' court-appointed conservators, was contacted. She provided consent for treatment, including surgery if necessary, but requested that no heroic measures be taken if her brother suffered cardiac arrest.

Despite treatment for suspected pneumonia and his generally debilitated condition, Mr. Helms progressively deteriorated while in the hospital and expired on June 28, 1987. The cause of death, according to the Medical Examiner was "bronchopneumonia, bilateral".

The Commission on Quality of Care for the Mentally Disabled learned of Francis Helms' serious medical condition and poor prognosis shortly after his admission to the hospital when, on June 25, 1987, a CHOWS social worker con-

tacted the Commission. Speaking on behalf of many hospital staff who attended Mr. Helms, the social worker voiced outrage over the deplorable condition in which Mr. Helms was found when he arrived at the CHOWS emergency room. Underlying this outrage was the fact that Mr. Helms had been known to human service agencies, which were supposedly monitoring or involved in his care.

Specifically, the social worker reported that eight years prior to his hospitalization, Mr. Helms was placed in the home of a private caretaker, Mrs. Verrone -- a living situation made possible through Mr. Helms' estate with the consent of his conservators. She also reported that for a number of years Mr. Helms' care in the Verrone household was monitored by Protective Services for Adults (PSA), an arm of the county Department of Social Services, responsible for providing protective services to vulnerable adults. Finally, the social worker reported that the Long Island Developmental Disabilities Service Office (LIDDSO), a district office of the State Office of Mental Retardation and Developmental Disabilities (OMRDD), was also involved in Mr. Helms' case and had received a request for services for Mr. Helms nearly one year prior to his June hospitalization, and had assigned a case manager. Upon receipt of the social worker's report, the Commission and its Mental Hygiene Medical Review Board initiated an investigation into the care and treatment of Francis Helms and the circumstances surrounding his death.

*The names of all persons referenced in this report are pseudonyms.



In this endeavor, Commission staff reviewed the records of Mr. Helms' inpatient stay at CHOWS, as well as case records maintained by the Suffolk County Department of Social Services' PSA and the LIDDSO. Investigation reports of the State Department of Social Services and the OMRDD, which also conducted reviews of Mr. Helms' care, were secured and reviewed, as were the records of the firm which managed Mr. Helms' estate. Commission staff also interviewed:

- Mrs. Verrone, Mr. Helms' primary caretaker;
- PSA staff involved in Mr. Helms' case;
- LIDDSO staff involved in Mr. Helms' case;
- Mr. Helms' private, community-based physician;
- Medical staff at CHOWS;

- Mrs. Harris, the Vice President of the investment firm which managed Mr. Helms' estate, who served as a liaison between service providers and Mr. Helms' conservators; and,
- Senior officials of the State Department of Social Services and the OMRDD.

This report summarizes the findings, conclusions and recommendations of the Commission and the Mental Hygiene Medical Review Board. Chapter II offers a case history of Francis Helms and the roles of various parties and agencies in his care. Chapter III presents a discussion on the adequacy of services provided to Mr. Helms and factors which influenced the adequacy of those services. Conclusions and recommendations are presented in Chapter IV.



CHAPTER II

Francis Helms and the Service System: A Case History

Francis Helms was born with Downs Syndrome in December 1926, and little is known about most of his life prior to 1979. At the age of 18 months, Francis was placed in a private facility on Long Island and was never again seen by his parents or siblings, two older sisters. In 1967, the private facility in which Mr. Helms had resided for nearly 40 years reportedly was converted to a nursing home, and Mr. Helms was transferred to an adult home in Hauppauge, Long Island, where he resided until 1979. During this period, Mr. Helms' father died and left a conservatorship account for Francis, as well as the income from a trust fund of several hundred thousand dollars established for Francis and his two older sisters. Francis' two older sisters were appointed as Francis' conservators by the State of Connecticut. The trust fund and conservatorship account were administered by a New York City-based investment firm, the Vice President of which, Mrs. Harris, became the primary liaison between Francis' sisters and his caretakers. The trust fund and conservatorship account increased in value under the administration of this firm.*

A sketchy picture of Mr. Helms, his functional abilities and daily life was gleaned in 1975 when the investment firm handling his trust became concerned over the adult home's billing practices and retained a private security firm to investigate the matter. In December of that year, a private investigator visited the adult home unannounced. The visit revealed no significant fiscal irregularities, and in his report to the investment firm, the investigator described Mr. Helms, based on his observations and adult home staff reports.

Mr. Helms, then 49 years old, was described in the investigator's report as being small in stature and light in weight, "probably weighing less than 100 pounds". At the time of the unannounced visit, he was found fully dressed in clean, neat, casual clothes, sitting in a lounge area with other clients, all of whom were older. The older clients called Mr. Helms "Frankie", talked to him and tended to look after him. According to staff of the home, Mr. Helms' expressive language skills were extremely limited, virtually non-existent; however, he could understand simple commands such as "go to the bathroom", or "put your clothes on". Reportedly, Mr. Helms could dress and feed himself and ate in the dining room with other clients. Staff, however, indicated that care was taken to cut his meat

*The value of Francis' property under conservatorship at the time of appointment of his sisters as successive conservators was approximately \$85,000. At the time of his death the conservatorship account exceeded \$200,000. The income from the trust fund was available for Francis' needs or comforts in the sole discretion of the fund's trustees, a sister and officials of the investment firm.



in small pieces and make his salads "more moist" than usual to prevent the possibility of choking. It was also reported that Mr. Helms could toilet himself, but required supervision and assistance in cleaning up afterwards. According to staff, Mr. Helms spent his time watching television with the other clients or sitting on the front porch watching cars go by. Behaviorally, he presented few problems, but would react strongly and negatively, by screaming, to changes in his environment such as a bedroom reassignment. The investigator noted in his report that Mr. Helms was assigned a semi-private bedroom, which was spacious, neat and clean, and simply furnished with two beds, dressers and chairs, and curtains on the windows. Mr. Helms at that time had no roommate.

The year 1979 marked significant changes in Mr. Helms' life and, in that year, Protective Services for Adults and the OMRDD became involved in his care.

In March 1979, Mrs. Harris received notice that the adult home in which Mr. Helms had been living was going into bankruptcy and that Francis, like all the other clients, would have to be moved in the very near future. The adult home's appointed "receiver" and a representative for the Suffolk County Department of Social Services advised Mrs. Harris that placement in the Suffolk Developmental Center (currently known as Long Island Developmental Center) would be the best option for Mr. Helms; however, they indicated that the center was full and that Mr. Helms would have to be placed on a waiting list. As an interim temporary measure, they recommended placement in the private home of Mrs. Verrone, a former employee of the adult home who knew Mr.

Helms. Mrs. Verrone was in her late seventies and took in boarders. She was also reportedly a nurse. The monthly charge for care in the Verrone residence would be \$600, which according to Mrs. Harris' records was roughly the equivalent of the adult home charge and "about half of what most nursing homes charge, even if they would take him".

Mrs. Harris and another representative of the investment firm visited both the adult home and Mrs. Verrone's home, which Mrs. Harris described as a palace compared to the adult home. According to Mrs. Harris' notes from the visits, health and fire precaution conditions at the adult home were bad and the ambiance was "shabby and depressing"; in contrast, Mrs. Verrone's house was well furnished and "homey". With the consent of Mr. Helms' conservators, secured by Mrs. Harris, Mr. Helms was transferred to the Verrone residence on March 9, 1979. Mrs. Harris observed the transfer and noted that Francis resisted the move and had to be carried bodily from the adult home by a representative of the Suffolk County Department of Social Services and two other men; she noted, however, that once at the Verrone residence, Mr. Helms was calm and that Mrs. Verrone seemed quite capable of "coping with him and making him comfortable". Approximately one month after Mr. Helms' move, Mrs. Harris was contacted by the State Department of Social Services and informed that a referral for services had been made to the OMRDD, and that a caseworker from the LIDDSO would soon visit and evaluate Mr. Helms.

In May 1979, an LIDDSO social worker visited the Verrone residence. She found Mr. Helms, along with another



male client, locked in a small (10' by 10') bedroom. The outside temperature was 90 degrees, yet all the windows in the room were closed and the room, with no ventilation, had a heavy stench. The social worker noted that Mr. Helms was non-verbal, unable to follow simple commands and totally dependent in all activities of daily living. According to the social worker, Mr. Helms seemed totally unaware of his surroundings. Mrs. Verrone reported to the social worker that Mr. Helms acted out somewhat, ripping things and smearing feces, and that he was being followed by a community physician, Dr. Patrick, who had placed him on a medication regimen of Valium, 5 mg., and Dalmane, 75 mg.

Although the social worker found that Mrs. Verrone was cooperative and interacted warmly with Mr. Helms, she concluded in her preliminary intake report that Mr. Helms' current residence was inappropriate to his needs, and recommended the placement be re-evaluated, and that psychological and medical assessments be conducted to determine an appropriate program for Mr. Helms.

After her visit, the LIDDSO social worker contacted Mrs. Harris and informed her of her concerns about the Verrone residence. Mrs. Harris, however, reported that conditions in the Verrone residence were superior to those in the home where Mr. Helms previously resided. The social worker agreed to discuss the matter with her supervisor and to call Mrs. Harris back. The LIDDSO social worker also informed the State Department of Social Services of her visit in a

June 15, 1979 telephone call, and forwarded the Department a copy of her written preliminary intake report.

There is no record of any further action by the LIDDSO on Mr. Helms' behalf for the next several years. The report of the LIDDSO to the State Department of Social Services, however, sparked the Suffolk County Department of Social Services' Protective Services for Adults (PSA) involvement in the case.

On June 15, 1979, a PSA caseworker and two nurses were ordered to visit and review Mr. Helms' living situation. They found four boarders in the home, all of whom appeared to require an HRF/SNF level of care. The home was reportedly neat, clean and well-furnished. However, the bedroom which Mr. Helms shared with a blind client, smelled of urine and feces. Mr. Helms was fully dressed, except for a belt, socks and shoes, which Mrs. Verrone reported he refused to wear. Mrs. Verrone reported that Mr. Helms had a tendency to scream. She also reported that he was being followed by Dr. Patrick, who visited the home every two months.

The PSA team concluded Mr. Helms was receiving adequate care, but that the case would remain open and PSA staff would periodically visit and monitor Mr. Helms. Mrs. Harris was informed of PSA's findings and plan of action on June 20, 1979.

Over the next two years, a PSA caseworker visited Mr. Helms at approximately six-month intervals. Notes from the visits indicated that Mr. Helms was usually found locked in his bedroom,



sometimes fully dressed, but often wearing only a shirt. His days apparently were spent sitting on the commode in the locked room, and Mrs. Verrone reported having difficulty with his smearing feces on the walls and ceiling, tearing clothes and screaming.

In September 1981, a different PSA caseworker visited Mr. Helms. Shocked by what he saw, he promptly called Mrs. Harris and reported that Mr. Helms' situation was deplorable. He explained to Mrs. Harris that, although Mrs. Verrone tries hard, she is old and Mr. Helms is difficult to manage; consequently, Mr. Helms was kept in a locked room, naked, sitting on a commode. The caseworker informed Mrs. Harris that he wanted Mr. Helms moved to Suffolk Developmental Center, and informed her that the process would take months. Mrs. Harris explained that she had always viewed the Verrone placement as a temporary measure and was under the impression that the Department of Social Services had placed Mr. Helms on a waiting list for the Developmental Center in 1979. Mrs. Harris, after consulting with Mr. Helms' sisters, authorized the PSA worker to pursue Developmental Center placement.

PSA records indicate that over the next six months, the PSA caseworker made several phone calls to the LIDDSO/Suffolk Developmental Center, but to no avail. According to PSA record entries, LIDDSO staff reported that they would not evaluate Mr. Helms and suggested that PSA attempt a nursing home placement. There is no evidence that this suggestion was followed-up and there is no LIDDSO record of these contacts.

During the period of 1982 through 1986, PSA staff continued to visit Mr. Helms in the Verrone residence. The visits became more frequent and occurred on a monthly basis, beginning with the assignment of a new PSA caseworker, Mr. Wayne, in the fall of 1985. During visits over this four-year period, Mr. Helms continued to be found naked, except for a shirt, locked in a bedroom, sitting on a commode. He continued to engage in behaviors, such as feces smearing, screaming and ripping up things, on a periodic basis, and was totally dependent in self-help skills. However, he was usually found to be clean and well-fed by Mrs. Verrone, who would spoon feed him meals and check on him in his locked room at various times during the day. Mrs. Verrone reportedly gave Mr. Helms his medications on an "as needed" basis, by mixing them in his food. She also reported that Dr. Patrick continued to visit and monitor Mr. Helms every several months. Caseworker notes from this period tended to indicate that Mrs. Verrone was caring and trying hard to manage a difficult situation.

During this period, most other boarders in the house had moved out and Mrs. Verrone, now in her 80's, began to experience health as well as financial problems. She had difficulty walking and was hard pressed to keep up with her utility bills. By July 1986, Mrs. Verrone was essentially bed-bound and spent her days in a "cluttered", as Mr. Wayne described it, bedroom near Mr. Helms'. Her care, as well as Mr. Helms', fell to her relatives and a neighbor.

In a July 11, 1986 letter, a PSA supervisor informed Mrs. Harris about Mr.



Helms' living conditions, that Mrs. Verrone was having some physical and financial difficulties, and that there were concerns about her ability to continue caring for Mr. Helms. The letter requested information concerning Mrs. Harris' long-term plans for Mr. Helms so that PSA could avoid the need for emergency planning in the event of a crisis. In response, on July 14, Mrs. Harris wrote that she had given PSA permission in 1981 to pursue placement of Mr. Helms in Suffolk Developmental Center and was under the impression that he was on a waiting list, although she never heard anything further since her 1981 authorization. In her letter, Mrs. Harris again expressed her and the family's wishes that Mr. Helms be transferred to the Developmental Center.

On July 18, Mr. Wayne from PSA wrote to the LIDDSO requesting an immediate evaluation of Mr. Helms for placement in an appropriate facility. He explained that Mr. Helms was severely retarded, requiring total care, and that he was potentially at risk, given his current care arrangement. Mr. Wayne further explained Mrs. Verrone's advanced age and health and financial problems. In response to Mr. Wayne's letter, a LIDDSO case manager was assigned to the case and applications for admission to the Center and consents to release information were sent to Mrs. Harris for signature by Mr. Helms' conservators. Several weeks later, however, after Mr. Helms' conservators had completed and, through Mrs. Harris, submitted the documents, the LIDDSO case manager informed Mrs. Harris in a September 30 letter that Long Island Developmental Center (formerly known as Suffolk Developmental Center) was under sanctions (for failure to meet

federal standards) and, consequently, could not accept new admissions. The LIDDSO case manager indicated that she would be willing to assist in finding a nursing home placement if the family so desired.

Mrs. Harris did not respond to the LIDDSO letter until December, when Mr. Wayne informed her that Mrs. Verrone was incapacitated and that Mr. Helms was being cared for by relatives and neighbors of Mrs. Verrone. Indicating that she did not previously know the severity of Mrs. Verrone's health problems or her incapacitation, Mrs. Harris wrote to the LIDDSO and authorized a search for a nursing home.

Through the winter of 1986-87, Mr. Wayne continued, as in the past, to visit Mr. Helms monthly, finding no significant changes in his living situation or condition. Mr. Wayne also advised the LIDDSO caseworker on how to secure a county Health Department evaluation of Mr. Helms for nursing home placement. During the same period, the LIDDSO attempted, with no success, to secure health records from Mr. Helms' physician, Dr. Patrick. As of February 1987, however, the LIDDSO case manager had neither visited Mr. Helms, nor contacted the Health Department for a nursing home evaluation.

On March 18, 1987, approximately eight months after being assigned to the case, the LIDDSO case manager visited the Verrone residence and Mr. Helms. She described the house as being "not clean and very cluttered". Mr. Helms was found naked, except for a shirt, sitting on a commode in his bedroom. His hair was long and dirty, but his shirt and bed linens appeared clean. Mrs. Verrone was



found in her bedroom, which was cluttered with piles of linens and clothing. A neighbor and Mrs. Verrone's sister reportedly were caring for both Mrs. Verrone and Mr. Helms.

The LIDDSO caseworker, who happened to be a nurse, reported to her supervisor that Mr. Helms' placement was totally inappropriate, due to his lack of stimulation and freedom. She, however, did not feel he was in imminent danger, nor did he appear to have any health problems; however, she did not examine him closely. Based on the caseworker's report, the LIDDSO deployed a psychologist and social worker from its crisis team who visited the home in April. The psychologist and social worker found the home to be filthy and cluttered. They reported that Mr. Helms, who was determined to function in the profound range of retardation, was thin, gaunt, dirty, and living in intolerable conditions; he was provided with minimal care and allowed to vegetate semi-nude in a small barren room. In their report to the DDSO, they voiced concern about the status of Mr. Helms' health and recommended immediate residential placement, a full-scale medical evaluation and an assessment of Mr. Helms' programming needs. In June, however, at a monthly LIDDSO staff meeting, the minutes of which were not recorded, Mr. Helms' case was discussed and the consensus of opinion was that he should be referred to a nursing home.

On June 19, 1987, Mr. Wayne made what would be his last visit with Mr.

Helms. He noticed that Mr. Helms was sitting on the floor of his room, leaning against the bed and, as usual, was wearing only a shirt. He asked Mrs. Verrone how Mr. Helms was doing, and she reported that he hadn't been eating well, but she attributed it to his sadness over the recent death of her dog, whom Mr. Helms enjoyed watching in the yard from the window of his room. Upon questioning during the course of this investigation, Mr. Wayne denied seeing any indications that Mr. Helms was ill, or afflicted with bedsores, but he indicated that he never saw Mr. Helms' upper torso, which was usually covered by a shirt.

On June 22, 1987, Mr. Wayne was informed by the LIDDSO case manager that Mr. Helms would not be admitted to Long Island Developmental Center and that the LIDDSO case manager would pursue a referral for a nursing home placement. The LIDDSO worker again asked Mr. Wayne for advice on how to arrange for a nursing home placement evaluation of Mr. Helms, and Mr. Wayne instructed her, as he had done six months previously in December 1986. That day, the LIDDSO caseworker, following Mr. Wayne's instructions, contacted the Health Department to arrange for Mr. Helms' evaluation; however, on the next day, before the evaluation could be conducted, Mr. Helms, dehydrated, malnourished and suffering from pneumonia and bedsores, was admitted to the Community Hospital of Western Suffolk, where he died five days later.



Chapter III

The Adequacy of Services Provided to Mr. Helms

During the last eight years of his life, Francis Helms lived in conditions unbecoming an animal: he was kept locked, semi-nude in a small, and at times filthy, foul-smelling room without a modicum of stimulation or opportunity to exercise the freedom or skills he once enjoyed. In his final months, he suffered from severe and multiple decubitus ulcers* and eventually, in a severely debilitated state, died as a result of pneumonia--conditions which, in the opinion of the Mental Hygiene Medical Review Board, may have been avoided had Mr. Helms been transferred earlier to a more appropriate level of care.

The tragedy of Mr. Helms' life and death is that for years private individuals, as well as public agencies entrusted with ensuring Mr. Helms' well being, knew, or should have known, of Mr. Helms' deplorable situation, yet failed to act responsibly.

Mr. Helms' sisters, for example, as conservators appointed by the State of Connecticut, were responsible for ensuring Mr. Helms' care, comfort and maintenance, as well as managing his financial affairs. Yet they delegated these responsibilities to an investment firm. When concerns were expressed, as early as 1979, about the appropriateness of Mr. Helms'

placement, neither his sisters nor the investment firm made independent inquiries or actively pursued other placement options. Not once during Mr. Helms' last eight years did his conservators or their agent proactively inquire about his well being. Rather, they served as passive recipients of negative reports on Mr. Helms' condition; and, in fact, after receiving such a report in September 1981, they never followed-up and nearly five years passed before they received another report. While it is beyond the Commission's purview to critique Connecticut's conservatorship program, it should be noted that by law Mr. Helms' sisters were required to provide the Connecticut Probate Court with annual reports on Mr. Helms' condition. None was filed and the court never followed-up to request reports.

Dr. Patrick, Mr. Helms' private physician, also may have abdicated his professional responsibilities in this case. As reported by Mrs. Verrone on many occasions, Dr. Patrick regularly visited Mr. Helms and prescribed medications. In Mr. Helms' CHOWS records Dr. Patrick indicated that Mr. Helms was under his care prior to admission, and in interviews with Commission staff, Dr. Patrick claimed that he visited Mr. Helms on a regular two to three month basis. Even if these assertions are true, one can safely assume that, since 1979, Dr. Patrick

*Upon examination of autopsy reports, medical records and photographs, the Mental Hygiene Medical Review Board determined that the ulcers found on Mr. Helms' body would have taken over a month to develop to the advanced stage at which they were found when he was admitted to CHOWS.



would have had ample opportunity to observe Mr. Helms' living conditions, confinement, isolation and lack of stimulation, as well as his debilitated physical health, if such was evident at the time of Dr. Patrick's last visit. Yet, Dr. Patrick never reported any problematic condition to any social service agency. In fact, Dr. Patrick maintained no record of his private care of Mr. Helms, never responded to requests for medical information reportedly made by the LIDDSO when Mr. Helms was alive, and, in the CHOWS discharge summary completed following Mr. Helms' death, omitted any discussion of the seriously debilitated state in which his patient arrived at the hospital. The Commission has referred Dr. Patrick's care and treatment of Mr. Helms to the Office of Professional Medical Conduct for review.

The tragic failure of responsible individuals to act on Mr. Helms' behalf was compounded by the fact that a service system specifically designed to protect vulnerable persons also failed Mr. Helms. As discussed below, the protective service system's response to Mr. Helms' situation and needs was marred by unclear expectations concerning fundamental quality of life issues, poor and unfocused service planning, and inadequate interagency cooperation and coordination. Although, subsequent to Mr. Helms' death, actions were taken to correct many of these problems in Suffolk County, discussions with senior staff of the State Department of Social Services and the OMRDD revealed that there are insufficient safeguards to ensure that similar problems do not exist in other regions of the State.

Response of the Protective Service System

To ensure the welfare of its citizenry, New York State offers, through the Department of Social Services, a program of services for adults who may be particularly vulnerable to harm. Specifically, Social Services Law requires local social services districts to provide services to adults "who, because of mental or physical dysfunction, are unable to manage their own resources, carry out the activities of daily living, or protect themselves from neglect or hazardous situations without assistance from others and have no one available who is willing and able to assist them" (SSL §473.1). Among the services to be provided by the local social services districts are:

- Investigating reports of impaired individuals who may be in need of protection;
- Assessing the individuals' situations and service needs;
- Arranging for appropriate alternative living situations; and
- Arranging, when necessary, for commitment, guardianship, conservatorship or other protective placements.

Social Services Law recognizes that the effective delivery of protective services is dependent upon a network of public and private service providers, and requires local districts to plan with other public and private agencies to assure maximum coordination and cooperative action in the provision of services.



In the case of Francis Helms, the Suffolk County Protective Services for Adults program, as well as the OMRDD, which shares an obligation to work with local governments to develop an effective, integrated and comprehensive system of services to mentally retarded and developmentally disabled persons (MHL§13.01), failed in their respective missions.

For years, case workers from PSA visited Mr. Helms and found him locked in a room, semi-naked. Sometimes the room reeked of feces and urine, most of the time Mr. Helms was left alone without any type of stimulation and with no program to train him, or maintain his skills in the activities of daily living. Most PSA workers seemed unperturbed by these conditions. The problem, as they viewed it and as expressed in an August 1985 case summary, was not Mr. Helms' ongoing state of deprivation, but "the future" and the fact that Mrs. Verrone was elderly and at some point would be unable to care for Mr. Helms.

This perspective, which reflects poor expectations regarding minimal standards of care and life for developmentally disabled persons, influenced service planning, which was often unfocused. For years, service plans developed by PSA on Mr. Helms' behalf were non-specific and, indicating that housing was suitable and that there were no health or mental health problems, called only for the continuation of home visits. Often, service plans said simply: "Our aim is to help you with the problem of adult protective services." There was no plan, and consequently no attempt, to assess Mr. Helms' health by contacting his private physician. There was no forthright plan or action, prior to the summer of 1986 when

Mrs. Verrone became incapacitated, to secure an alternative placement for Mr. Helms, despite the fact that he required a more intensive level of care based on his needs, but was residing in an unlicensed boarding home.

Commission staff, noting the absence of any other service agency, particularly the LIDDSO/OMRDD in Mr. Helms' PSA service plans, were informed by PSA staff that, based on their experience, they viewed the LIDDSO/OMRDD as a closed system of care, unwilling to become involved with PSA cases and, as such, PSA did not view the LIDDSO/OMRDD as a resource to provide services for Mr. Helms. The PSA perspective on this issue rings true when examining Mr. Helms' history.

In 1979, upon the referral of the State Department of Social Services, LIDDSO staff visited Mr. Helms in the Verrone residence and, finding him locked in a room, isolated and totally dependent for care, concluded in the intake report that the placement was inappropriate and that Mr. Helms' required further medical and psychological assessments. However, the LIDDSO apparently never followed up on this preliminary assessment and recommendations.

In 1981, when a different PSA worker newly assigned to the case discovered Mr. Helms naked, locked in a room and devoid of any stimulation or programs to assist him in daily living skills, he contacted the LIDDSO. But, according to PSA records, he was informed that the LIDDSO would not conduct an evaluation and was advised to pursue a nursing home placement. (Advice which the PSA worker never followed.)



And, in the summer of 1986 when Mrs. Verrone became incapacitated and PSA requested that the LIDDSO conduct an "immediate" evaluation of Mr. Helms who was potentially at risk, given the age and health and financial problems of his current care provider, the LIDDSO took eight months before it conducted the first home visit and assessment of Mr. Helms. During this interval, without the benefit of a personal assessment, the LIDDSO staff concluded that Mr. Helms could not be admitted to the developmental center, due to federal sanctions, and that they would pursue a nursing home placement.

It should be noted that the federal sanctions imposed on the developmental center at that time did not preclude admissions to the center. They precluded medicaid reimbursement for new admissions; Mr. Helms had sufficient personal funds to pay for his stay at the center. According to senior OMRDD officials interviewed, the imposition of federal sanctions indicates that a center is having difficulty meeting standards of care and the admission of new clients is discouraged, but admission decisions should be made on the basis of assessments of individual need. This was not done in Mr. Helms' case. It should also be noted that, although LIDDSO staff determined that developmental center placement was out of the question due to intermediate sanctions and because they would pursue a nursing home placement, six months elapsed between the time that the LIDDSO was advised by PSA on how to arrange a nursing home placement and when it took action on the advice, by which time Mr. Helms' condition had deteriorated to the point that he was

admitted to the hospital and, within a week, expired.

In short, neither PSA nor the LIDDSO fulfilled their shared obligation to provide Mr. Helms with protective and necessary services.

Systemic Issues

Both the Department of Social Services and the OMRDD conducted reviews of Mr. Helms' care and treatment and the circumstances surrounding his death. Both reviews were critical of the local PSA and LIDDSO's handling of the case. Issues of service planning, supervision and interagency cooperation were cited in these reviews. Within one month of Mr. Helms' death, the local PSA and LIDDSO began discussions, which resulted in a formal interagency agreement calling for joint agency emergency -- as well as routine -- visits and assessments of protective service cases involving developmentally disabled persons. The agreement specifies the time frames for joint assessments and prescribes a mechanism for interagency service plan development and review which ensures that representatives of both agencies meet on a regular basis to formulate plans and monitor compliance with such. (See Appendix A)

According to reports of representatives of the LIDDSO and the local PSA, these agreements have enhanced each agency's understanding of the other's role and capabilities and have paved the way for joint and successful intervention on behalf of potentially endangered developmentally disabled persons, as well as cooperative involvement in and review of ongoing cases. The agreements also have set the stage for the cross-fertilization of



values, expectations and problem solving strategies.

On the basis of interviews with senior State officials, however, there appears to be no assurance that similar cooperative arrangements exist between OMRDD district offices and local social services districts across the State. There is no statewide assurance that developmentally disabled persons who may be in need of protective services will receive timely and appropriate assessments and services.

According to State OMRDD officials, there are no directives or policies requiring that other Developmental Disabilities Service Offices establish cooperative agreements with local PSA's. Additionally, State OMRDD officials did not know whether any DDSO, outside of the LIDDSO, has an agreement for cooperative services with local PSA's. Senior State OMRDD officials also indicated, when shown the time lapse in the LIDDSO's response to Mr. Helms' case, that there are no statewide policies or standards on time frames for personal assessments of individuals referred to the OMRDD for protective services. Such time frames for visits and assessments, the officials indicated, are left to the judgment of individual professionals. And, while senior staff indicated that "emergency cases" should receive priority attention, they could not operationally define "emergency" or time frames for "priority attention."

Senior Department of Social Services officials were equally uninformed about local PSA efforts to network with OMRDD district offices in the provision of protective services to mentally retarded/

developmentally disabled adults. State Department of Social Services officials could not report how many, or if any local PSA Offices, had interagency service agreements with local DDSO's, besides the Suffolk County/LIDDSO agreement which grew out of the Francis Helms' case. State DSS officials also could not report how many persons on PSA case roles are developmentally disabled, as their data base on PSA cases does not include information on the nature of persons' disabilities.

Although State Department of Social Services officials reported undertaking two initiatives to improve interagency cooperation in PSA, these initiatives seem to be intrinsically limited and slow moving.

According to State Department of Social Services staff, since 1981 local districts have been required to identify in their consolidated service plans and annual updates specific activities that they will undertake to improve intra- and inter-agency coordination and cooperation in the delivery of protective services. Department of Social Services regulations (18 NYCRR §457.7) identify the types of public and private agencies in local communities which should appropriately be incorporated into the network of protective services. However, State Department of Social Services staff indicated that staffing constraints limit their ability to assure local district compliance with these requirements. Additionally, State Department of Social Services officials reported that they have endeavored to secure Memoranda of Understanding with agencies on a State level to facilitate the provision of PSA services on a local level, and they presented as an example a



Memorandum of Understanding developed with the State Office for the Aging as a prototype for agreements with sister State agencies. This Memoranda of Understanding, however, had been in development since at least 1984 when the Commission investigated another PSA related case* and, as of the spring of 1988, no other state level PSA interagency agreements had been made by the Department of Social Services.

In short, although the LIDDSO and PSA of Suffolk County, in light of the Francis Helms' case, have arrived at an agreement which provides for joint agency intervention, service planning and review of developmentally disabled adults in need of protective services, there exists no state-wide policies or agreements which would ensure similar protections for vulnerable disabled adults in other regions of the state.

*In the Matter of Jerry Smith - A Resident of Fulton County, May 1984



CHAPTER IV

Conclusion and Recommendations

The story of Francis Helms' final years and death underscores the need for New York State's program of Protective Service for Adults. Mr. Helms--despite his wealth, despite the appointment of conservators by a Connecticut State Court, and despite the monitoring of a community based physician and the best efforts of an elderly frail caretaker--lived his final years in a state of deprivation and neglect. The story, however, also vividly demonstrates how unfocused service planning, poor interagency cooperation and coordination, lack of follow-up and muddled expectations can seriously defeat the mission of Protective Services for Adults. For months and years, PSA caseworkers visited Mr. Helms in his state of deprivation; their primary concern, however, was not the existing condition in which Mr. Helms lived, but what would happen if the placement failed.

So limited is the availability of residential placements for developmentally disabled adults living in the community that this wretched home and its chronic neglect were viewed as an asset worth preserving; it permitted officials charged with protecting disabled adults to avoid confronting other priorities which made a safe and decent residence unavailable to Mr. Helms.

The OMRDD, which should have shared in the protective mission of PSA and was called upon several times for assistance on Mr. Helms' behalf, failed to respond in a timely and appropriate

manner. And both agencies failed to follow-up on leads regarding nursing home placements.

Mr. Helms' legacy is a greatly improved protective service system in Suffolk County. Following his death, Suffolk County Department of Social Services and the Long Island Developmental Disabilities Services Office agreed on a formal system of joint agency involvement on behalf of developmentally disabled persons requiring protective services. The agreement sets forth provisions and time frames for interagency assessments, emergency and routine site visiting and periodic case review. As a by-product, the agreement also sets the stage for a cross-fertilization of values, expectations and problem solving strategies among individuals who are on the front lines of protective and developmental disabilities service provision.

The challenge presented by repeating Mr. Helms' story is ensuring that developmentally disabled persons requiring protective service in all regions of the State receive the best and fullest attention and services possible. Toward this end, the Commission recommends that:

- The State Department of Social Services and the State Office of Mental Retardation and Developmental Disabilities develop a Memorandum of Understanding affirming their respective and shared roles in providing services to developmentally disabled persons deemed to be in need of protection. This agreement should require local Social Services Districts and DDSO's to develop agreements to



ensure interagency cooperation and coordination regarding protective cases involving developmentally disabled adults. Local agreements should address processes and time frames for:

- Intake and referral
- Assessments
- Joint service planning and
- Periodic case review

Local agreements should also call for periodic interagency orientation and training for staff to acquaint and update them on the roles of and services provided by the respective agencies.

- The Office of Mental Retardation and Developmental Disabilities should establish minimal time frames and criteria for visiting and assessing developmentally disabled persons who are reported to be at-risk.
- The Department of Social Services should modify its data base on protective services cases to capture information on the nature of disabilities afflicting people who require protective services.

Finally, although the Commission recognizes that the conduct of Mr. Helms' conservators was within the purview of

the State of Connecticut Probate Court, which failed to request and critique reports by the conservators, the Commission believes that the telling of the Francis Helms story presents the occasion for New York State's judicial system to reflect upon its own operations. The Francis Helms case graphically illustrates the vitally important role conservators and courts play in protecting the interests and well-being of vulnerable persons, and the tragic outcome when either party fails to carry out its responsibilities. In light of this case, it would behoove New York State courts to examine their role and activities relative to conservatorship to determine whether any prophylactic measures are necessary to prevent a similar tragedy and safeguard the well-being of conservatees. Such measures may include requiring that conservators personally visit and assess the well-being of their conservatees, and the adequacy of services provided on their behalf on at least an annual basis. Such assessments should be included in the conservators' annual reports to the court. Additionally, it may be advisable that conservators ensure that conservatees are physically examined by a physician on an annual basis, and that the physician's report is included in their annual report to the court.

Appendix A

Memorandum of Understanding Between Suffolk County Department of Social Services and Long Island Developmental Disabilities Services Office



STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

LONG ISLAND DEVELOPMENTAL DISABILITIES SERVICES OFFICE
415A OSER AVENUE, HAUPPAUGE, NY 11787

Arthur Y. Webb
Commissioner

October 18, 1988

Mr. Thomas P. Harmon
Assistant Director
Policy Analysis and Development Bureau
Commission on Quality of Care for the
Mentally Disabled
99 Washington Avenue, Suite 1002
Albany, New York 12210

Dear Mr. Harmon:

As requested, enclosed please find a copy of the Memorandum of Understanding between the Long Island D.D.S.O. and the Suffolk County Department of Social Services, Adult Services Bureau.

If you have any questions concerning this document, please contact me.

Sincerely,

IRA ZIMMERMAN
DEPUTY DIRECTOR, COMMUNITY SERVICES

IZ:gmd
ENC.

CC: I. Canuteson



Being retarded never stopped anyone from being a good neighbor.

MEMORANDUM OF UNDERSTANDING

The following is a Memorandum of Understanding between the Adult Services Bureau of the Suffolk County Department of Social Services (hereinafter "ASB") and the Long Island Developmental Center, acting on behalf of the New York State Office of Mental Retardation and Developmental Disabilities and operating through the Long Island Developmental Disabilities Services Office (hereinafter "LIDDSO").

WHEREAS: ASB is required to provide protective services for individuals as defined in Article 9-B Section 473 of the Social Services Law.

WHEREAS: LIDDSO is responsible for seeing that services are provided to developmentally disabled individuals as defined in Chapter 978 § 1.03 (22) of the Mental Hygiene Law.

NOW, THEREFORE, LIDDSO and ASB hereby agree to work cooperatively and within the procedures outlined herein as follows:

Section 1. Client Referral Process

(ASB to LIDDSO)

- a. In the event that ASB makes a referral to LIDDSO, such referral by ASB shall include all medical with written consent, psychological and psychosocial assessments when available. Further, ASB shall include, with its referral, a detailed explanation of the request for services.
- b. Within 2 weeks of the receipt of the ASB referral, LIDDSO and ASB will cooperate with

each other and participate in a joint case management visit by both parties with the client. Such visit shall be arranged and coordinated by ASB in consultation with LIDDSO.

c. Within 7 working days of the joint visit, LIDDSO will advise ASB on whether or not it appears that the referred party may be eligible for services available to developmentally disabled persons.

d. Within 3 months of the receipt of the referral to the LIDDSO by ASB in which LIDDSO has advised that the referred party is eligible for services to the developmentally disabled, the LIDDSO and ASB will work jointly and cooperatively with each other to complete a case plan for the developmentally disabled individual required and managed by ASB.

Section 2. Client Referral Process

(LIDDSO to Adult Services)

- a. ASB with respect to clients referred from LIDDSO to ASB, will visit with the referred individual within 72 hours of the referral from LIDDSO, in accordance with regulations of NYSDSS. LIDDSO will cooperate with ASB and will have staff available for
 - a. Joint visit if so requested by ASB.
 - b. The LIDDSO will forward to ASB all medical, psychological and psychosocial assessments available on the referral made to ASB. Further, LIDDSO shall include a detailed explanation of the request for services.
 - c. If, as a result of a visit conducted pursuant to paragraph (a) of this section, ASB determines that the person is in need of, and is eligible for, the services of ASB, the LIDDSO will be so advised by ASB.

LIDDSO and ASB will cooperate with each other and participate in a joint case management visit with the client. Such joint visit will be arranged and coordinated by ASB in consultation with LIDDSO.

Within three (3) months of the receipt of the original referral to ASB by LIDDSO, in which ASB has advised that the referred party is eligible for, or is in need of, the services of ASB, the LIDDSO and ASB will work jointly and cooperatively with each other to complete a case plan for the developmentally disabled individual required and managed by ASB.

Section 3. Joint Responsibilities

a. Both parties agree to share information concerning the referred party at such times and in such amounts as may be necessary to administer service plans for the referred party. However, such information shall be shared at least on a quarterly basis and for as long as both parties continue joint services to the client.

b. Any act or decision, by either party to discontinue services or to otherwise make a significant change in the service plan, must be communicated in writing to the other party, at least 30 days prior to the change.

c. Both parties agree to review on a quarterly basis, all unresolved (shared) cases. This review shall be carried out in a conference session with the appropriate supervisory level personnel from both parties. Cases to be considered at those sessions shall be written as short status summaries which will be sent to each party at least five (5) working days prior to the scheduled meeting. Unless otherwise agreed to by both parties, all quarterly meetings will be held on the first Tuesday of the first month of the quarter at 9:30 a.m. at the LIDDSO offices.

Section 4. Emergency Referrals


- a. Immediate referral shall be made to LIDDSO by ASB which concerns a case not previously known to ASB and found, upon initial contact, to be in crisis, with possible eligibility for LIDDSO services.
- b. Telephone referral shall be made by ASB Assistant Directors, or their designated agents, to the Family Support Services Director of the LIDDSO, with request for expedited joint visit by ASB and LIDDSO for the purpose of arriving at an immediate plan to address the situation. ASB and LIDDSO will make every effort to cooperate with each other to conduct a joint visit within five (5) working days of the immediate referral. Such joint visit shall be arranged and coordinated by ASB in consultation with LIDDSO.
- c. Any services or temporary arrangements by LIDDSO or ASB which are used as part of an emergency response plan shall be confirmed in

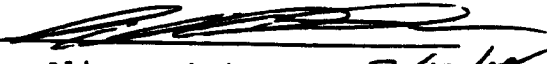
an exchange of letters between the parties within five (5) working days of the joint visit under this section.

d. Cases originating through the emergency referral system shall subsequently be handled according to guidelines for regular referrals to ASB and for joint responsibilities, with regard to case decisions, information-sharing, quarterly review conferences, once the initial emergency has been resolved.

Section 5.

This Memorandum of Understanding may be cancelled by either party upon 30 day's notice to the other party.


Ivan Canuteson
Director
Long Island Developmental
Disabilities Services Office


Alice Amrhein 2/22/88
Commissioner
Suffolk County
Department of Social Services

Appendix B

Responses of State Department of Social Services and the Office of Mental Retardation and Developmental Disabilities

NEW YORK STATE

DEPARTMENT OF SOCIAL SERVICES

40 NORTH PEARL STREET, ALBANY, NEW YORK 12243

CESAR A. PERALES
Commissioner



December 6, 1988


Dear Chairman Sundram:

This is in response to your November 4 letter, in which you requested my comments on the Commission's draft report entitled "In The Matter of Francis Helms". Since this report addresses issues pertaining to the delivery of Protective Services for Adults (PSA), I asked staff from the Department's Division of Adult Services to review this document.

For the most part, the Department's review found the draft report to be accurate and we support its recommendations. However, our review revealed that the Department's PSA interagency planning and service delivery requirements were not adequately reflected on pages 28 and 29 of this report. In each year since 1981, local departments of social services have been required to identify in their Consolidated Services Plans (CSPs) and annual plan updates at least two specific activities they will be implementing to improve intra and inter-agency coordination and cooperation in the delivery of services to PSA clients. The types of activities which must be addressed in the CSPs and annual updates are developing interagency agreements and written policies and procedures with aging, health, mental health, legal and law enforcement agencies, as well as developing procedures among appropriate units within the department of social services. Also, psychiatric and developmental centers and community mental health services are among the specific agencies with which districts must develop interagency relationships. These planning requirements are supported by specific language in Section 457.7 of the Department's regulations, which requires the districts to meet with other services agencies and providers for the purpose of establishing specific roles and responsibilities regarding the delivery of services to PSA clients. Therefore, I don't believe that the problem is with our standards, but with our ability to assure local district compliance with these standards due to serious staffing constraints.

In closing, I want to thank you for providing us with an opportunity to comment on the draft report. I trust that the final version of this report will address our concerns. If you have any questions about our comments, please contact Deputy Commissioner Judith Berek of the Division of Adult Services at 432-2974.

Sincerely,


Cesar A. Perales
Commissioner

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



STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 12229
(518) 473-1997

ARTHUR Y. WEBB
Commissioner

March 8, 1989

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

Dear Chairman Sundram:

Thank you for the opportunity to review and comment on the draft report of the Commission's investigation into the death of Francis Helms. The circumstances leading to Mr. Helm's demise, as delineated in the Commission's report, have been compared with the internal investigation which had been conducted by the Office of Mental Retardation and Developmental Disabilities (OMRDD). While some differences have been found in the two reports, they do not alter the basic findings or impact on actions already taken by OMRDD. These differences are, therefore, provided as an addendum.

The conclusions reached in the Commission's report are consistent with those made in the agency's internal investigation and reflect subsequent actions taken immediately at Long Island DDSO. OMRDD's action included:

- o Immediate investigation.
- o Analysis and improvement of the internal operations of the placement and case management unit of Long Island DDSO.
- o Establishment of biweekly review of all Long Island DDSO-served "individuals at risk" by the Deputy Director of Community Services.
- o Establishment of Memoranda of Understanding with both Suffolk and Nassau Counties' Department of Social Services to coordinate planning, service and monitoring of all joint protective service cases involving developmentally disabled individuals.



Right at home. Right in the neighborhood.

Mr. Clarence J. Sundram
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- o Establishment of professional conduct and advocacy expectations training within the interdisciplinary team process and new employee orientation.
- o Increased training of all employees in advocacy responsibility to protect the civil and human rights of individuals requiring OMRDD services.
- o Formal disciplinary actions taken against staff whose professional conduct failed to meet agency standards.

The above actions at Long Island DDSO have proven effective in meeting the needs of individuals who are developmentally disabled and in "at-risk" situations. It must also be pointed out, however, that one significant impediment that contributed to the facility's failure to provide appropriate care to Mr. Helms has been removed; namely, reluctance of staff to admit persons to the developmental center. The imposition of intermediate sanctions against the developmental center for failure to meet Medicaid standards played a role in this case. The focus of the DDSO became the protection of the services to existing individuals residing in the developmental center. This effectively shifted consideration of services available to meet Mr. Helms' needs from the developmental center to a community system that could not accommodate all the requests it had for residential care. This, however, does not excuse the failure to recognize that Mr. Helms' situation required immediate action by Long Island staff as well as the Adult Protective Service.

Subsequent to the improvements in case management and coordination with Adult Protective Services at Long Island, the agency has used the Helms' case for further training and sensitization with each of the agency's DDSOs. Communication was directly initiated at the Executive Deputy Commissioner level of OMRDD and the Department of Social Services.

The Helms' case study was incorporated into the agency's training for directors, deputy directors, treatment team leaders and personnel officers on client abuse and neglect. The program of instruction entitled, "Concepts, Principles and Issues Requiring Employee Corrective Action Within NYS OMRDD," delineates the agency's expectations of employees when encountering abuse and neglect situations. This two-day program was first presented to the Commissioner, his Executive Cabinet and selected central office and field staff on December 10 and 11, 1987. It was then presented to all DDSO directors and their deputies in April of 1988.

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Further training in this area will be conducted via the Bureau of Staff Development and Training's three regional programs in 1989. A contract has been submitted for approval to further extend this training to the staff of all twenty DDSOs during 1989. The agency has also started the process of revising the statewide curriculum for all new employees to assure that staff have a clear understanding of their responsibilities as advocates for the individuals they serve.

The Helms' case, the internal investigation, programmatic changes made within Long Island DDSO's community structure and improvements in coordination with Adult Protective Services were presented in the forum of the Deputy Commissioner's Monthly Meetings with DDSO directors. Each director was asked to analyze the working relationship currently existing within their catchment area's local Departments of Social Services and, where necessary, initiate enhancements.

Some facilities and localities have developed highly organized, frequent meetings, involving not only Department of Social Services Adult Protective Services, but other major human services providers, as well. Our survey further indicates many examples of cross-training of respective case management staffs, joint conferencing and planning of shared cases and clear assignment of monitoring responsibilities. In some instances, existing identification and referral mechanisms with the Office of Mental Health and other providers have been expanded to include adult protective services staff. All of these activities which assure coordination of effort are accomplished without formal agreements.

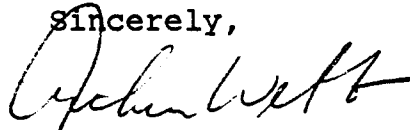
Both the OMRDD investigation and the Quality Care Commission's Report correctly identify that poor professional expectations, judgement and service were primary contributors to Mr. Helms' tragic life and subsequent death. This individual failure on the part of various Adult Protective Service and Long Island DDSO staff permitted Mr. Helms' living situation to deteriorate. His life was negatively affected by external considerations over which he had no knowledge or control. The failure of trained, presumably competent professionals to take effective action in spite of external realities is the focus of OMRDD's planning to assure other cases like Mr. Helms' will not occur.

Mr. Clarence J. Sundram
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The Commission's recommendations for a Statewide Memorandum of Understanding between OMRDD and the Department of Social Services, and an establishment of common, statewide timeframe and criteria for visiting at-risk, developmentally disabled individuals attacks the problem identified by the report, at the wrong end of the organization. It is our belief that emphasis should be placed at the point of contact between the developmentally disabled citizen and the staff charged with initially serving him. By assuring that these staff are competent, trained in their responsibility to protect the individual's civil and human rights, held accountable for their decisions and have their cases reviewed regularly, we address the shortcomings of staff as cited in the report, directly and affirmatively. Furthermore, by demonstrating our willingness to conform our services to the local Adult Protective Services' capabilities, we will achieve the cooperation, coordination and meaningful communication that was absent in the Helms' case.

Finally, the DDSO directors understand and are committed to assuring that developmentally disabled individuals requiring protective services will have their needs met, and that an effective means of identifying those individuals and integrating them within the service system will exist in each DDSO. I appreciate the Commission's examination of the death of Francis Helms as another means of hastening the achievement of these objectives.

Sincerely,

A handwritten signature in dark ink, appearing to read "Arthur Y. Webb", written in a cursive style.

Arthur Y. Webb
Commissioner

Enclosure