Crossing the Line from Empowerment to Neglect: The Case of Project L.I.F.E.

Clarence J. Sundram CHAIRMAN

Elizabeth W. Stack William P. Benjamin COMMISSIONERS

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NYS COMMISSION ON QUALITY OF CARE FOR THE MENTALLY DISABLED

Preface

The investigation described in this report beganwith a call to the Commission from a resident of a supportive apartment alleging that money was being taken from his food allowance to pay for his high telephone bills and that consequently he did not have enough to eat. This call marked the first step in a review of operations of the Project L.I.F.E. supportive apartment program which serves 72 persons with developmental disabilities residing in 60 apartments in New York City.

Commission review activities included on-site announced visits (September 16 and 20, 1992 and March 30 and 31, 1993), interviews with residents and staff, and the review of case files and financial records. While the initial complaint was not substantiated, in the course of the Commission's review, a number of serious problems were identified which affect the health and safety of the residents of the supported apartments, including:

- summary discharges from the apartment program and the failure to provide due process procedures to the residents involved, in violation of Office of Mental Retardation and Developmental Disabilities (OMRDD) regulations (Report pp. 5-8);
- the failure to ensure the provision of necessary medical and mental health services to residents who need them, including ensuring that medication administration is safe (Report pp.11-14);
- the failure to report and appropriately investigate and review serious incidents as required by the Mental Hygiene Law and OMRDD regulations (Report pp. 8-11);
- inadequate supervision of residents and intervention when residents were believed to be in abusive or dangerous situations (Report pp. 14-16); and
- the absence of service planning and guidance from staff which goes beyond cooking, cleaning

and shopping and addresses the pressing needs of the residents.

During the course of the Commission's work with Project L.I.F.E., it became apparent that the agency lacked an adequate understanding of its regulatory responsibilities and had no quality assurance system to warn administrators that their actions and inactions were in violation of such important regulations as:

- the requirement to insure that medications be properly administered;
- that serious incidents be reported and investigated; and
- that discharged residents have an appropriate place to live.

Lacking an understanding of the regulations which govern its operation and provide basic protections to the residents, Project L.I.F.E. administrators believed, and continue to believe, that the objections of the OMRDD and the Commission to aspects of the agency's operations stem from a failure to appreciate a holistic approach to the treatment of persons with developmental disabilities and a related failure to understand the concept of choice. While the supportive apartment regulations require an agency to provide "sufficient oversight and guidance" to ensure that each resident's health, safety and welfare are addressed (14 NYCRR 686), Project L.I.F.E. administrators state that they will not force unwelcome services on anyone unless there is imminent danger to a resident or a member of the community. Additionally, they note that the regulations are too restrictive and their failure to comply stems from "reasoned judgement."

As presented in this report, the Commission believes that the agency did not exert "reasoned judgement" in dealings with some vulnerable residents and, in the name of choice, neglected its obligation to provide people with adequate services to protect their safety and well-being.

A draft report containing the Commission's findings and the supporting documentation was shared with Project L.I.F.E. and the OMRDD on July 6, 1993. Project L.I.F.E. responded with a voluminous rebuttal which, in effect, charged that the Commission had drawn erroneous conclusions because it had not reviewed all portions of the residents' records (Project L.I.F.E. did not send the complete records as requested by the Commission). the records contained wrong information, and/or the Commission misconstrued the contents of the records and interviews. In an effort to ensure the accuracy of its report, COC staff met for ten hours with eight representatives of the agency. Following an 11 week wait for information requested by CQC at this meeting, the Commission revised the draft report and resubmitted it to the Project L.I.F.E. and the OMRDD.

The OMRDD's response to the report is included as Appendix B and indicates that the Office found many of the same problems with the agency as the Commission had and is determining what actions to take to insure that the services provided by Project L.I.F.E. are consistent with the requirements of Mental Hygiene Law and regulations. Project L.I.F.E's 200-page response to the report again asserted that the report was flawed because it misconstrued facts and failed to understand the principles of normalization which undergird the agency's philosophy. In a few instances where the agency provided documentation that supported their view, the report was changed. In the majority of cases, where the agency's rebuttal was only an assertion, and the case record and/or interview notes revealed no support or revealed evidence to the contrary, the report was not changed. It is important to note that in adopting this final report, the Commission resolved any reasonably disputable matter in Project L.I.F.E.'s favor. Most importantly, however, the Project L.I.F.E. response contained a list of corrective measures which it asserts have been implemented since the Commission's earliest involvement in September 1992. (See Appendix C of this report.)

The completion of this investigation was substantially delayed by the failure of Project L.I.F.E. to initially produce all of the records requested by

the Commission; by its assertion that significant actions, required to be documented, occurred but were not recorded; and by its extremely unorthodox record-keeping practices whereby record notations, which the agency asserts are erroneous, are nevertheless signed by supervisors and circulated to other staff without any indication that their accuracy should be questioned. These record-keeping practices permit Project L.I.F.E. to argue positions that are flatly contradicted by its own records.

Finally, in the course of this investigation, the Commission received unsigned letters from sources with apparent knowledge of the operations of Project L.I.F.E. which alleged that the administration of the agency had been altering records, and counseling both its staff and residents to withhold information and obstruct the inquiries of both the Commission and the certification staff from OMRDD. Since these allegations also affect the on-going recertification process of OMRDD, the Commission has deferred follow-up of these allegations to OMRDD.

The lessons to be learned from the Project L.I.F.E. investigation are particularly important as we move to serve people in more individualized settings supported by less rigorous regulatory frameworks. Without regulations dictating everything from square footage in bedrooms to the quantity and kind of recreation, these programs depend all the more on the good character and professional competence of the program's administrative and clinical staff. Without such leadership, staff are illequipped to balance the tasks of safeguarding the safety and well-being of individuals with mental disabilities with those of empowering these same individuals to take responsibility for their lives.

Many residents of supportive apartment programs are persons with developmental disabilities who have known many failures and who are reluctant to "buy into" any service agency's agenda. They are difficult to serve and call upon the full creative talents of staff. Some of the Project L.I.F.E. residents are no exception. Serving these individuals well requires an ability to formulate and implement creative solutions to problems—an ability which rests on a clear understanding in any particular case of when the line between empowerment and neglect has been crossed. As detailed in this report,

which rests on a clear understanding in any particular case of when the line between empowerment and neglect has been crossed. As detailed in this report, in too many instances, Project L.I.F.E. administrators could not see the line.

This report represents the unanimous opinion of the members of the Commission.

Clarence J. Sundram, Chairman

Elizabeth W. Stack, Commissioner

William P. Benjamin, Commissioner

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Staff Acknowledgements

Project Director Elizabeth J. Chura

Project Staff
Pamela A. Williams
Corinne Romanotto
Stephen Hirschhorn

Publications Staff
Christine Blackman
Man Lee Chan
Marcus Gigliotti

Introduction

This investigation began in the summer of 1992 in response to a complaint received from a resident in the Project L.I.F.E., Inc. supportive apartment program and subsequent conversations with the OMRDD Bronx DDSO office. Specifically, it had been alleged that Project L.I.F.E. did not ensure proper medical attention for some of the residents, that residents were not informed of the agency's policies and procedures, that the agency was refusing to give some residents their food and/or personal allowance monies because they had not paid their rent or other bills, that no one was assisting residents to secure a job, that coaches (direct care staff) were not visiting residents when scheduled, and that many apartments were in "bad shape."

In response, Commission staff made announced visits to the program on September 16 and 22, 1992. They obtained copies of the Incident Review Committee (IRC) minutes, the minutes of the Weekly Staff Meetings, the maintenance log for one year, and selected policies and procedures for the employment and housing program. In addition, CQC staff reviewed five residents' records and visited their apartments. Commission staff met with the Executive Director, the consulting psychologist, the Associate Director, the Fiscal Officer, the Field Coordinator, the Housing Director, and two housing coaches. Preliminary findings were discussed with the Associate Director during the review and in subsequent telephone contacts.

Following the initial visit, CQC staff called the NYC Regional Office of OMRDD expressing concerns about the operation of the program and learned that the office had investigated the issues related to money management on August 31, 1992. In response to concerns which arose during the OMRDD site visit and the concerns raised by the Commission, the OMRDD Regional office indicated that it would conduct a program/management

audit (not a certification review¹) on October 13, 14, and 15, 1992.

The review cited the inadequacy of the records of residents of the housing program, noting that they were "extremely scant with limited information relative to admission, initial planning, assessment of need, annual reevaluation, program planning and revision."

A report of the findings and recommendations of the OMRDD audit was forwarded to Project L.I.F.E. on February 12, 1993, with a request for a plan of correction by April 1, 1993. The report studied six areas: consumer empowerment, habilitation and support services, family supports, Human Rights Committee, financial interests of each individual, agency self-evaluation and governing body. Most relevant to this report, the review cited the inadequacy of the records of residents of the housing program, noting that they were "extremely scant with limited information relative to admission, initial planning, assessment of need, annual reevaluation. program planning and revision." It also noted the need for the agency to ensure that family members are invited to annual planning meetings. The reviewers recommended the establishment of a Human Rights Committee and the drafting of a formal written policy on the management of residents' funds as well as the establishment of individual interest-bearing accounts for each resident. However, in general, the reviewers found that

Certification reviews measure the performance of a program against the regulatory standards for that specific treatment modality.

systems were in place to meet the needs of program participants and keep families advised of critical issues. A copy of the report is included as Appendix A

Although the transmittal letter accompanying the report noted that Project L.I.F.E. was free to reject any recommendations, the agency accepted, in part or in whole, all of the recommendations and promised appropriate action to implement them.

The Commission again received complaints that were consistent with the earlier ones. On March 30 and 31, 1993 CQC staff conducted another announced review to the main office of Project L.I.F.E. and several apartments. During this visit, CQC staff reviewed the records of five participants who had been discharged, records of five current residents, incident reports for February and March 1993 and weekly Staff Supervision Meeting minutes. CQC staff also secured some 1992 financial reports (I-990, cash disbursement journal and an agency financial statement). COC staff met with the Executive Director and other members of the administration. the President of the Manhattan Self Advocacy Group and several residents. Again, on-site findings were discussed with the senior administrator.

On July 6, 1993, the Commission sent Project L.I.F.E. and the OMRDD a 30-page draft report of our findings and recommendations. Project L.I.F.E. sent back a response 21/2" deep and weighing five pounds which contained case record information not sent in response to our initial request and which alleged that the Commission and its reviewers failed to appreciate their holistic approach to care and treatment: "The CQC investigators consistently confuse philosophical differences with substantive inadequacies in the program" (July 30, 1993 response, II). Commission staff then met with eight representatives of the agency for 10 hours in formal discussion of our report and their response. During these discussions Project L.I.F.E. administrators presented additional information and acknowledged that some information they had previously given us (e.g. work histories of residents) and some information that we had obtained from case records was erroneous and had not been corrected in the course of supervision or other quality assurance activities. This process resulted in some changes in the report; in other instances where the Commission's findings

remained the same, but Project L.I.F.E. disagreed with our interpretation of the significance of the finding, we have indicated this in the text of this report. In any instance where we believe the issue truly lay in a grey area, the Commission gave Project L.I.F.E. the benefit of the doubt and did not include it in the report.

Project L.I.F.E.: History and Development

According to its own description, the Project L.I.F.E. agency was formed by parents, families, and developmentally disabled adults who were either underserved, or unserved by the existing state social services system. Not mentally ill or mentally retarded, they fell between the cracks, and the existing models and approaches just did not work. These were individuals who did not perceive themselves as disabled and believed that with appropriate supports they could both work and live independently in the community.

The first programmatic initiative launched by Project L.I.F.E. in 1986 was supported employment. Project L.I.F.E. opposed segregation of the disabled and was committed to integration, independence, inclusion, and productivity in employment. The goal of the supported employment program is to "place and sustain chronically unemployed developmentally disabled individuals in ongoing employment, at minimum wage and above, with salaries directly paid by the employer."

Presently, the target population of the agency consists of individuals whose primary diagnosis is developmental disability. Most are behaviorally challenging, yet have positively responded to the Project L.I.F.E. programs and support services. Without appropriate services they are at high risk for homelessness, hospitalization, and crime. Most do not have a stable family support system, or have little in the way of a positive support system outside of Project L.I.F.E. According to the agency, ninetynine percent of Project L.I.F.E. participants are failures of the system and have been rejected or discharged from other agencies and programs, which could not "handle" them.

In 1989, the program opened its first supportive apartments licensed and funded by OMRDD serving approximately 14 people in 9 rented apartments in the Bronx and Manhattan. The majority of the residents of these first apartments were also being served in the supported employment program.

In 1990, Project L.I.F.E. began several years of significant expansion for the program with the addition of ten co-op apartments (apartments owned by the agency) in the Bronx for 15 people. In 1991 and 1992, Project L.I.F.E. added 41 apartments or co-ops. In total, the agency presently operates 60 apartments and employs 11 coaches plus supervisory and support staff in the residential component of the program.

In 1991, the agency was granted a Comprehensive Medicaid Case Management Contract and presently serves 69 people, the majority (83%) from the residences. Under this contract, each participant receives a maximum of 72 hours of case management a year with a minimum of one monthly contact. These services are designed to assist Medicaideligible people to "ensure the coordination and follow-up of medical, therapy, recreational, educational, vocational, residential [services], and maintenance of benefits."

The agency enjoys a professional relationship with City College of New York. Graduate psychology students work as *job* coaches for which they receive a stipend and professional supervision while learning through on-the-job training.

Project L.I.F.E.: Program Philosophy

The following description of the Project L.I.F.E. philosophy was excerpted from the preface (written by the Project L.I.F.E. Executive Director) to the June 30, 1993 response to the Commission's draft report:

It was clear that the cultural biases and assumptions of the traditional social system impaired services for the Project L.I.F.E. population. Traditional approaches created more tension, more difficulty, greater family dysfunction, deterioration in behaviors,

anger, frustration, etc., which destructively and negatively impacted on the quality of life for the individual and their family. The challenge was to transcend the cultural biases and approaches of the larger traditional system and working in a holistic manner, meet each individual's needs, in a flexible individualized way at a pace which was commensurate with each individual's ability.

For Project L.I.F.E., appropriate interventions flow from the following: 1) responding to the segments of problematic behavior in terms of the whole person; 2) identifying and responding to the strengths of the individual and using those strengths to come to grips with problematic behaviors. 3) Removing as many obstacles as possible from the environment of the participant (e.g., excessive rules and regulations) which in the past have resulted in conflict (i.e., in the family, school, agency, etc.). Our participants have experienced much frustration and failure. This has resulted in a great deal of anger and desperate strategies to protect their shattered self-esteem from further failure; items one, two and three, coupled with the support and sensitivity of our staff contributes to the development of meaningful positive relationships and trust. Finally and most important is the fact that our approach is based on common themes found in the inner experience of individuals with a developmental disability. In Project L.I.F.E. the holistic approach dominates and is reflected in interaction with participants (and staff) on a daily basis.

What is a Supportive Apartment and Who Lives There?

In 1987, OMRDD supportive apartments were renamed supportive community residences, although the use of the term "apartment" provides a more accurate description of the living arrangement. The regulations governing this residential option (14 NYCRR 686.8) define a supportive community residence as a residential environment which approximates an independent living situation. It pro-

² Project L.I.F.E. response, June 30, 1993, (p. 16).

Each resident of a supportive community residence should receive, according to the regulations, sufficient oversight and guidance to ensure that his or her health, safety and welfare are addressed.

vides residents with practice in independent living under the "oversight, guidance and assistance of the persons having case management responsibilities... in accordance with each individual's needs." Each resident of a supportive community residence should receive, according to the regulations, sufficient oversight and guidance to ensure that his or her health, safety and welfare are addressed. This may be provided through daily face-to-face contact, or, at a minimum, a once per week site visitation with the resident. The regulations note that anyone who requires residential oversight and guidance in excess of an average of 21 hours a week is not considered appropriate for this program. Oversight and guidance includes, but is not limited to, training and practice in independent living skills and health care management, personal problem solving and counseling, giving direction, providing support and encouragement, increasing the resident's awareness of responsibilities and opportunities and reviewing the individual's adjustment and development

Supportive community residence regulations also specifically address the issue of discharge from the program and expressly preclude discharge except to a setting which can more appropriately meet the resident's needs and which is actually available at the time of discharge. The agency is required to develop policies and procedures for handling a resident's objection to the discharge or the proposed alternative setting.

The regulations further specify that each person in a supportive community residence shall have at least an annual review of his/her progress completed by a program planning team which must include, at a minimum, the resident, the staff member responsible for coordination of the resident's

program plan and someone familiar with the administration of the program. The plan of service formulated by the team must contain sufficient information to enable one to track the provision of necessary services, including an annual evaluation of the resident's ability to take medications safely, a description of how the plan intends to minimize or eliminate needs and/or increase strengths and level of independence, and the identification of those skills which will be worked on by the resident with the person providing oversight and guidance, commonly called a coach, at Project L.I.F.E.

Because each resident's primary long-term goal is to learn to live independently, regulations specifically note the expectation that residents under the age of 55 will participate in a "full schedule of daily activities, educational activities or occupational pursuits of sufficient duration and intensity as to make for a meaningful life."

Commission Findings

Both Commission reviews at Project L.I.F.E. revealed that the residential program, which, as described in the regulations, serves persons who are capable of taking care of many of their own needs with supervision and guidance, was failing in numerous instances to adequately assess the risk of harm that the behaviors of some of the individuals posed for themselves and others, and failed to take effective and timely corrective measures. Conversations with several members of the administration revealed that they were often reluctant, even in extreme cases, to challenge the choices/wishes of

All suggest a failure to meet the obligation to protect the health, safety and welfare of residents, an obligation which forms the cornerstone of a program providing quality care to persons with developmental disabilities.

the program participants and render necessary, but unwelcome, services. In some instances, it appeared that the staff involved did not appreciate the seriousness of some of the events occurring in the lives of the residents. In other instances, the agency took actions which jeopardized the safety of residents without ensuring an adequate safety net.

As will be shown in the examples which follow, some practices of the agency, such as summary discharges, and the absence of meaningful daily activities clearly violate State regulations. All suggest a failure to meet the obligation to protect the health, safety and welfare of residents, an obligation which forms the cornerstone of a program provid-

ing quality care to persons with developmental disabilities.

Discharge Practices

As noted, State regulations governing the discharge of persons from supportive community residences (14 NYCRR 686.8) require each agency to establish policies which preclude discharge except to a setting which can more appropriately meet the person's needs and which is actually available at the time of the projected discharge. As illustrated below, the agency flagrantly disregarded these regulations in several instances and discharged people without warning and recourse to due process, and without documenting where they were going and how they would be better served there.

Resident P.N.³ was dispossessed from her supportive apartment on February 3, 1993 for failure to pay her rent and refusal to discuss the issue.

A handwritten note in P.N.'s record (unsigned) dated November 20, (1992) documents a telephone call with a contact at the Social Security Office, who explained to the coach that "if P.N. could not handle her money with Project L.I.F.E., she (contact) will notify the courts to appoint a payee". Project L.I.F.E. did not believe the appointment of a representative

The agency flagrantly disregarded these regulations in several instances and discharged people without warning and recourse to due process, and without documenting where they were going and how they would be better served there.

All initials used in this report have been changed to protect the identity of the individuals.

⁴ Project L.I.F.E. response, June 30, 1993, (p.19).

payee was appropriate because P.N. "had opened a checking account without assistance and conducted her financial transactions independently and successfully." In short, P.N. was not incapable of handling money, in the view of Project L.I.F.E., rather she was knowingly refusing to pay the rent. As a result, the agency barred her from her apartment on February 3, 1993.

A note dated November 3, 1992 documents a coach's visit with P.N. at St. Luke's Hospital, where she was hospitalized following an asthma attack. The coach discussed with P.N. that the Agency Comptroller had personal allowance (\$94) and food money (\$48) for her if she would go to her bank and withdraw \$508.00 for her rent. Other notes record various attempts to talk out the matter with P.N. She was uncooperative each time.

The record concludes with a report from staff that they entered P.N.'s apartment on February 3, 1993 while she was away, packed her things and left the bags outside her apartment door "for her to take when she got back." This, according to Project L.I.F.E., was an aggressive tactic to persuade P.N. "to come into the office to work out her financial obligations."

The record concludes with a report from staff that they entered P.N.'s apartment on February 3, 1993 while she was away, packed her things and left the bags outside her apartment door "for her to take when she got back."

CQC staff were informed that P.N. is in a Bronx BDSO respite bed, but it is unclear how she was subsequently placed there, as there was no evidence of discharge planning in P.N.'s record. Project L.I.F.E. defends the lack of a discharge plan by stating that this move was not an attempt to discharge P.N., but only an attempt to get her to address the rent problem.

B.K. was arrested on March 9, 1993 following an alleged assault on a staff member. When B.K. was released by the police on his own recognizance and returned to his apartment the following morning, he found that Project L.I.F.E. had changed the locks on his apartment door. Reportedly, this was done with no notice to B.K. who complained to Mental Hygiene Legal Services (MHLS). The agency explained this action by noting that it considered B.K. a substantial and imminent risk to residents and staff.

According to a MHLS letter to the Director of the Bronx BDSO, on March 12, 1993 the counsel for Project L.I.F.E. proposed that B.K. receive 30 days of psychiatric treatment during which time he was not to live in his Project L.I.F.E. apartment, but could return if he continued to cooperate with psychiatric treatment. However, on March 17, 1993 the MHLS attorney for B.K. received a faxed transmittal from Project L.I.F.E. indicating that the agency was not going to honor the agreement and had scheduled an exit interview with B.K. on March 19, 1993. During a meeting with Commission staff, the Executive and Associate Directors acknowledged that the agency had proposed placement for B.K. in the Bellevue Shelter.

On June 22, 1993, the BDSO Director instructed the agency to readmit B.K., as he had fulfilled the requirements initially agreed upon. Project L.I.F.E. objected and refused to take B.K. back. Several months later all parties agreed that B.K. could move into an apartment at another Project L.I.F.E. site where no female clients of Project L.I.F.E. were residing. Shortly thereafter, in November 1993, MHLS represented B.K. in a hearing to determine whether he had been properly discharged. The Hearing Officer ruled that the discharge violated OMRDD regulations, as B.K. was not advised of his right to object to the discharge and be heard and was not maintained in his current level of programming while the appeal was heard. The Hearing Officer recommended the following:

Project L.I.F.E. should readmit B.K. back into the supported apartment program;

⁵ Project L.I.F.E. response, June 30, 1993, (p. 19).

- Project L.I.F.E. should provide B.K. with the supports he needs, including a coach who is knowledgeable and sensitive;
- Bronx BDSO should assist Project L.I.F.E. to locate appropriate employment for B.K.;
- B.K. should actively cooperate with Project L.I.F.E. "in pursuit of appropriate employment and coaching services";
- B.K. should continue to receive counseling;
- Follow-up of June psychiatric evaluation of B.K. should be addressed; and
- A progress report on B.K.'s status three months after his return to Project L.I.F.E. should be made to the BDSO which should, in addition, monitor his status regularly.

Project L.I.F.E. appealed the decision, citing that they were given insufficient notice of the November hearing and key staff, including the Executive Director and Chief Psychologist, were not able to be present. They argued more broadly, however, that B.K. was still a danger to others, and "the safety and welfare of participants and staff cannot be threatened solely to meet due process regulations."

The appeal was denied, and B.K. was readmitted to the Project L.I.F.E. housing program on February 22, 1994. In May 1994 the assault charges were still pending.

A review of the housing record of E.L. revealed several entries noting that he had been refusing to pay rent since August 1991 and was only sporadically available for coaching. An undated letter to E.L. also notes his failure to pay rent since September 1991 except for a partial payment in January 1992. [Project L.I.F.E. later stated that this information in its records was in error and supplied COC with other documents revealing E.L. had made contributions of various amounts toward his rent in four months in 1991 and three months in 1992 (including full payment in January 1992) until his discharge in July 1992]. A letter dated December 11, 1991 from the Executive Director to E.L. officially warned him that he was not in compliance with the policy regarding rent contribution. Review of the notes from January 2, 1992 through July 1,

1992 finds that E.L. was "avoiding contact with coaches and not paying his rent." There were additional reports of E.L. not having food. Of note, E.L.'s Annual Plan of Service, dated June 3, 1992 and signed by the Executive Director, reports that E.L.'s objective for the current year was "to help E.L. comply with his rent contribution...once this is out of the way coaching can focus on all ADL skills necessary for E.L. to maintain living independently in the community. The main objective is to get the financial matter resolved so that we can progress with ADL skills". On July 1, 1992 E.L. was discharged. Project L.I.F.E. staff verbally reported to CQC that E.L. had vacated his apartment, and they didn't know his whereabouts at the time. E.L. signed an undated letter informing him that he had been discharged for failing to pay rent and cooperate with his housing coach. Project L.I.F.E. administrators state that E.L. returned sometime after his discharge and signed the letter at that time.

With information provided them by the Commission, the OMRDD reviewed the discharges of six former residents of Project L.I.F.E.. This review identified deficiencies related to due process in five of the six cases.

Although we were informed by Project L.I.F.E. that E.L. is in a Bronx BDSO respite bed, there was no discharge plan in the record or note about where he was going at discharge. An unsigned handwritten note dated August 12, 1992 reports that a Social Worker from Cardinal Cooke Medical Center contacted Project L.I.F.E., and reported that E.L. was living on the streets. The author of this note wrote, "I explained our situation, the lack of compliance of E.L. contributing his SSI for months. I told him (caller) that E.L. had not been discharged but his absence from his apartment and his choice not to comply was interpreted by us as his voluntarily leaving the program."

⁶ Project L.I.F.E. letter to OMRDD Commissioner, December 30, 1993.

With information provided them by the Commission, the OMRDD reviewed the discharges of six former residents of Project L.I.F.E.. This review identified deficiencies related to due process in five of the six cases. The findings of the OMRDD review, communicated in writing to the Executive Director on May 26, 1993, stated that the agency's "current practices are indicative of a systemic pattern of noncompliance." A plan of correction was requested within 10 days. The first plan was deemed unacceptable, as it primarily refuted the findings and contained no corrective actions. The second plan was acceptable, to the OMRDD since it included a promise by the agency to advise program participants of their right to object to aspects of their care and treatment and to permit the exercise of these rights as identified in OMRDD regulations.

Incidents, Serious Situations and Service Plans

The program has an obligation under both Mental Hygiene Law (Section 29.29) and regulations (14 NYCRR 624) to report, investigate and review activities which constitute an incident. Reportable incidents are defined by regulations as significant events or situations which endanger a resident's well-being. A serious reportable incident is one which, because of severity or sensitivity of the situation, must be immediately reported to the OMRDD. Reportable incidents include injuries which require medical or dental treatment beyond first aid, leaves without consent, death, and medication errors which result in marked adverse effects or which jeopardizes the resident's health or welfare. Also included are possible criminal acts; allegations of physical, sexual or psychological abuse; the unauthorized or inappropriate use of restraint, seclusion, or aversive conditioning; mistreatment; neglect; violations of a resident's civil rights; and sensitive situations.

Project L.I.F.E. policies note that in addition to incidents as defined in the regulations, the agency will report as an incident "any event that takes place that may be considered different from normal circumstances or out of the ordinary that involves residents, staff, consultants, contractors, volun-

teers, parents, correspondents, visitors or any other such persons and/or buildings or equipment."

The obligation to report, investigate and review incidents provides a fundamental safeguard to residents. It aims to ensure that programs examine the circumstances of incidents, assess cause and accountability, and take steps to ensure that the incidents do not recur. Failure to engage in this process in good faith leaves residents vulnerable to unnecessary and repeated suffering and can prevent them from getting the clinical and other services that they need to correct their behaviors which may be contributing to the incidents, or from learning the skills they need to protect themselves.

Review of the Incident Review Committee minutes and the weekly staff meeting minutes reveals several incidents which would appear to have required reporting and which were not treated as reportable incidents. These included incidents of street drug use, domestic violence between two program participants, the unexplained absence of a resident from his apartment for several days, the hospitalization of residents for medical and psychiatric conditions, and the arrest of residents. Project L.I.F.E. contends that it used "reasoned judgement" in not reporting certain incidents.

A review of the Incident Review Committee minutes for 1991 reveals that the Committee met seven times during the year and discussed only two incidents—one, a medical problem and the second, the incident involving F.C. who reportedly became upset when his roommate made plans which did not include him. The IRC minutes do not describe what happened when F.C. became upset, so it is impossible to evaluate the seriousness of the incident. The Committee recommended that in the future "an attempt will be made to make sure that F is involved in an activity when his roommate doesn't include him."

In addition, residents displayed other behaviors which required reporting, assessment or intervention. Some of these behaviors had a significant impact on the lives of the residents themselves, fellow residents and sometimes the community at large. Documentation was not available to substantiate that the incidents were reported as necessary and that treatment options were discussed and a plan of action formulated.

C.P. reportedly carries a straight razor with him at all times. According to the Project L.I.F.E. escort, C.P. has lunged at coaches when they have knocked on his door for their scheduled visits. C.P. lost one job in 1988 when he slashed items with pins in a stationery store where he worked. A job coach reportedly stood with him for almost eight hours because after he slashed items -- "He stood against the wall and wouldn't respond." In 1989 he defended himself by grabbing a razor in a health club where he worked.

When asked why the agency did not address this behavior and continued to allow C.P. to carry the razor, the Executive Director replied that it was C.P.'s right to possess a razor, just as it was his right to have a screwdriver or a hammer. The agency further elaborated that its treatment goal (not documented) is to "provide him with internal security in place of the need to carry a razor."

Another resident E.C. reportedly refuses to work and spends his time taking part of his wall and mattress apart, piece by piece. The Executive Director and Associate Director explained, "When he is done, we make him pay to have a new wall put back up or to replace the mattress. This is what he chooses to do with his time. If we don't ask anything of him, he stays calm and is no problem." They also reported that this information is not in his record because "we can't document that we let him do this, people will think it's crazy, but it works with him." Project L.I.F.E. staff later clarified that because E.C. has an obsessive/compulsive disorder, interrupting these behaviors is very stressful to him. They also acknowledged that the statement that he had to pay for the repair of the wall was in error.

E.C.'s parents signed an agreement in April 1992 indicating that E.C. would be referred for a medical evaluation and counseling immediately, helped to find employment, and moved to another apartment if that became necessary. This meeting and agreement were occasioned by E.C.'s problematic behaviors, including knocking on tenants' doors and peering through peepholes, accosting a neighbor, and going onto the roof.

Most importantly, E.C.'s service plan addresses none of these serious behaviors. Although Project L.I.F.E. reports that E.C. receives counseling by the agency's Consulting Psychologist weekly, no documentation was provided to substantiate this claim.

K.V. has an eating disorder causing him to weigh over 400 pounds, has borderline diabetes, and suffers from periodic bedwetting. Initial information from Project L.I.F.E. indicated that K.V. was employed in Project L.I.F.E.'s Employment Program from February 1987 through the date of his admission into the Housing Program in April 1989 when he quit his job. Subsequent corrected information from Project L.I.F.E. indicates that he worked quite regularly through June 1990. Since then he has held numerous jobs for short periods of time. The Executive Director explained that presently K.V. enjoys going to the main office of Project L.I.F.E. a few days a week to do odd jobs, socialize and, in general, maintain his work skills.

K.V.'s record contained a handwritten contract dated June 25, 1992, which reads:

Iunderstand that because I curse and threaten to hit people and break things that I am banned from Project L.I.F.E. office for a month. On July 23rd I can return to the Project L.I.F.E. office. If I act out in the apartment or neighborhood, I will go to a psychiatric hospital and my mother will be informed of everything good and bad that I do.

This agreement is signed by the Executive Director and witnessed by four other people. K.V. did not sign this agreement. Again, his threatening to hit people and break things is not addressed in his plan of service.

K.V.'s record contained a Team Case Conference report dated August 26, 1992 documenting that he became upset when he was not included in dinner plans and subsequently locked himself in his apartment and began throwing things out the window. He reportedly had a knife. Another program participant contacted the Housing Director who called 911. K.V.'s mother was also called by Project L.I.F.E. She met her son at the hospital. The Housing Director was disciplined for not ensuring that Project L.I.F.E. staff were present on-site when the police arrived. K.V.'s mother also saw this as a

⁷ Project L.I.F.E. response, June 30, 1993, (p. 31).

serious mistake which placed her mentally disabled son at risk.

While assuring CQC staff that the Project L.I.F.E. policy regarding calling the police was common knowledge, administrators acknowledged it is not written.

The service team discussed strategies for handling future incidents and in notes from that meeting stated that police should be called "only if life is in danger." Project L.I.F.E. administrators state that these minutes misrepresent their position, although they were signed by a senior administrator.

The important issues remain: This essential policy is not written and not well understood, no incident report was filed, and this out-of-control behavior was not addressed in K.V.'s service plan.

As noted in this example and referenced in the introduction to this report, Project L.I.F.E. case records and other documents contained entries with erroneous information. During our extended meetings with them, administrators explained that although they had reviewed the material (some of these documents were co-signed by supervisors) and recognized the errors, it was agency practice not to add clarifying information or in any way indicate that the document was in error. These documents were then circulated to the three Project L.I.F.E. service components—residential, employment and case management—with errors uncorrected. In explaining this practice, Project L.I.F.E. administrators noted that when erroneous entries are identified, they are used as training examples at the next weekly staff meeting.

In addition, contrary to agency policies regarding maintenance of records, every record reviewed by CQC staff contained numerous undated and unsigned entries, or inadequate reviews of service plans, or inadequate documentation of residents' progress.

Staff Supervision Meeting minutes dated October 28, 1992 describe a discussion regarding the problems other tenants at the Riverside Drive apartments were having with the Project L.I.F.E. residents. The complaints noted the residents' "undesirable" guests, late hours, inappropriate dress, and use of foul language. It concluded that "some neighbors are afraid." The minutes further explain

that two Project L.I.F.E. staff will attend the Coop's Board of Directors meeting on October 29 "to help the Board members to view the problems realistically because our participants are vulnerable and easy targets." In response to the complaints, one resident was spoken to privately and a meeting of all Project L.I.F.E. residents of this apartment complex was convened. There, residents were reminded of security procedures.

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As in other instances, program plans of the individuals involved were not amended to address these issues.

The owner of the Crueger Avenue buildings showed CQC staff a petition and gave a copy to the Associate Director in their presence. Dated February 1993 and signed by 35 neighbors, it charged that some residents of the Project L.I.F.E. program are not capable of living in the community with minimal assistance, but require 24-hour on-site supervision. It alleges that these individuals roam the building in their underwear, destroy property, pick up other tenants' children to kiss them, lunge at people, take other people's coupon flyers, curse, repeatedly overflow their bathtubs causing water damage to ceilings and walls of the apartments below them, and defecate and urinate in the hallways and are inattentive to their personal hygiene.

Supervision Meeting minutes dated February 22, 1993 document the agency's knowledge of the petition and note problems with "T.R. (underwear and urinating) and K.V. (cursing)." They note that staff will speak to T.R. advising him that he risks losing his apartment. A memo dated August 5, 1992 documents the agency's other response -- a meeting of all Crueger Avenue Project L.I.F.E. residents to discuss complaints from neighbors.

It was reported to the residents at this meeting that the landlord had received many complaints about their playing loud music, leaving trash in front of the building, yelling from the windows, arguing loudly and cursing in hallways. Participants urged each other to avoid these actions and suggested such alternatives as renting a movie, going to the park, taking a nap, or calling another resident.

While the meeting was likely beneficial, the Commission is concerned again that it appears that none of these situations resulted in team reviews to address each participant's behavior and the need for training and/or group or individual counseling to assist those residents having difficulties to live amicably with their neighbors. While some of these behaviors are only annoying and inconsiderate rather than dangerous, all would likely have a chilling effect on the willingness of neighbors to welcome persons with mental disabilities into their neighborhoods in the future.

In response to CQC findings, Project L.I.F.E. administrators note long-standing animosity by the owner of the Crueger Avenue apartments and Project L.I.F.E. residents which stems from the time he took ownership of the buildings in 1991.

Project L.I.F.E. administrators state that "in regard to the claims in the petition, a) some reflect an isolated occurrence and not a general pattern of behavior, b) most are untrue and c) some are distortions of the facts." As an example, the agency cites the allegation that residents roam the building in their underwear. According to Project L.I.F.E., this is incorrect and based on the fact that one person was taking his garbage to the compactor room, which is on his floor and a few feet away from his apartment, wearing only underwear.

The agency maintains that it addressed all legitimate allegations, although the interventions were not necessarily documented.

Medical Care/Oversight

As noted earlier, the regulations governing the operation of a supportive community residence require that each resident "shall have sufficient oversight and guidance to ensure that his or her health, safety and welfare is addressed." The regulations also require that the agency identify the degree of risk to each resident in his/her use of medications and for ensuring that "such risks do not inordinately affect the health, safety and welfare" of any resident.

The Commission's review raised serious question regarding the medical support afforded to some residents, about staff's understanding of the medical/health needs of the residents, and about the administration of medication.

During our tour of F.N.'s apartment, his sheets and quilt were stained with urine. His coach explained that F.N. is often incontinent during the night. When CQC asked the cause of the incontinence, the coach reported that he did not know, and when questioned whether any medical follow-up had been undertaken to rule out a physical cause, he reported that F.N. had not received medical attention for this condition.

The Commission's review raised serious question regarding the medical support afforded to some residents, about staff's understanding of the medical/health needs of the residents, and about the administration of medication.

Project L.I.F.E. response, June 30, 1993, (p. 43).

Project L.I.F.E.administrators defended the coach's lack of information, noting that case management records (which contain information regarding a resident's mental and physical health) are not available to coaches. Instead, coaches are verbally advised by other coaches about the significant health problems of the residents to whom they are assigned. Thus, it was reasonable, Project L.I.F.E. administrators argued, that the coach did not know that the enures is was psychologically-based. (Project L.I.F.E. administrators presently state that case management files have always been available to housing coaches and cite that coaches sometimes perform case management functions. This is directly contrary to the earlier conversations recorded above.)

The practice of verbally communicating the health needs of residents to coaches who rotate clients every three months, and the unavailability of a medical record for reference, is a poor management practice which substantially increases the likelihood that important information will not be shared or will be misunderstood, or its significance miscalculated. In addition, this method of information sharing carries no assurances that staff have received training about particular pathologies which they may need to respond to. All in all, the system places a tremendous burden on housing coaches and places acutely and chronically ill residents at risk. The following cases illustrate this concern:

The practice of *verbally* communicating the health needs of residents to coaches who rotate clients every three months, and the unavailability of a medical record for reference, is a poor management practice which substantially increases the likelihood that important information will not be shared or will be misunderstood or its significance miscalculated.

There is no indication that the staff member who authored the housing note appreciates the confusion evident in the entry, as he/she identifies no need to clarify whether B.T. truly is hepatitis positive or has high glucose levels and whether these require medical treatment or monitoring. One can also reasonably question whether the coach had received any training regarding hepatitis B, including information necessary for his/her own protection. On the other hand, the case management note shows no familiarity with B.T.'s problem of believing that blood glucose monitoring will keep his hepatitis in check.

S.B. is a 38-year-old woman diagnosed with Mental Retardation, Diabetes Mellitus, Hypertension, Hyperlipidemia, Open Angle Glaucoma, Obesity, Gout, and a Seizure Disorder. She was admitted into Project L.I.F.E.'s housing program in April 1990. Incident Review Committee minutes dated November 1991 recommend that S.B. move to a supervised apartment because of her health needs. These presently include monitoring of her diet and the administration of insulin twice a day and seven or more oral medications, including cardiac medications. This move had not occurred as of May 1994.

Contrary to the information contained in her Annual Plan of Service dated May 5, 1992, that "coaches see S.B. three times daily to do meal preparation, food portioning and meal planning [which] has helped greatly to minimize her health problems," S.B.'s record contains a letter dated July 10, 1992 from her physicians reporting that they have noted a deterioration since she was last seen and that she needs close supervision of her diet and medication. Additionally, they state that "due to

B.T.'s coaching notes for September and October 1992 document that he "becomes hepatitis positive and presents with a high blood glucose level", which "leads him (B.T.) to believe he is diabetic." In response, B.T. purchased a machine for "testing his blood sugar level to keep tabs on his hepatitis." At the same time, case management notes on October 21, 1992 indicate that B.T. "has a good understanding" of the implications of his hepatitis diagnosis.

⁹ Medications as of May 18, 1993.

the problems it is our (physicians') recommendation that S.B. be placed in a more closely supervised surrounding where her diet and medications can be monitored and dispensed properly, since her compliance is very poor."

Approximately a week after the letter from the doctor, it was determined that S.B. required "someone medically trained, licensed to dispense medication as well as nutritionally trained to do food preparation, such as a visiting nurse." This memo also notes that the physician believed that a visiting nurse would not be sufficient, and he recommended that S.B. join a diet group. S.B. did join "Weight Watchers" and her coaching notes document an increase in agency supervision to assure S.B.'s compliance with medical appointments.

In an undated document, the agency applied for a Home and Community Based Waiver from the OMRDD. This plan calls for S.B. to remain in an apartment with her husband and receive assistance from a certified home health care aide twice daily to assist/monitor the preparation and injection of insulin and blood glucose testing, monitor self administration of oral medications, and monitor S.B.'s blood pressure. She would continue to receive habilitation services from Project L.I.F.E. 3-6 hours daily, focusing on personal hygiene, housekeeping, money management and shopping. Project L.I.F.E. would also provide 24-hour emergency support.

This application was denied by the OMRDD in June 1993 until the "investigation and certification issues related to the Supportive Community Residence program are resolved." Presently, S.B. has been receiving visits five days a week from a certi-

fied home health care aide and services from the Project L.I.F.E. housing coaches and case management personnel.

The Home and Community Based Waiver application describes S.B. has having the skill to draw up and inject her own insulin, but, because of lack of attention to detail, may do this inaccurately. It also notes that it is not uncommon for S.B. to be several hours late in administering her medication.

These notes indicate that Project L.I.F.E. has not met its responsibility under regulations to assess the degree of risk surrounding this resident's use of prescription and nonprescription medications and ensure that such risks do not inordinately affect her health, safety and welfare [14 NYCRR 686.8(3)]. Regulations additionally require that each individual's plan of service address medication administration and ensure that is it performed by the person herself (if capable), by a health care professional, or by a staff member who has completed an approved course in medication administration [14 NYCRR 633.17]. The staff member monitoring S.B.'s medication administration had not received this training; indeed no Project L.I.F.E. staff had had such training.

In October 1993 the OMRDD instructed the agency's Executive Director that she must familiarize herself with the regulatory requirements for the administration of medications. Several weeks later in response to a certified letter from the OMRDD noting serious deficiencies in a similar case, ¹⁰ Project L.I.F.E. stated that it had acquired nursing services and that its staff would be trained in medication administration.

A September 23, 1993 certification review by the OMRDD revealed a "serious condition which could pose a threat to the health and well being of one individual" as it related to the administration of medication. The individual cited had severe chronic medical conditions including diabetes, hypertension, and angina. The plan of correction submitted by Project L.I.F.E. a week later was unacceptable as it asserted that the individual was "independent in self-administration and could independently address his chronic health care needs"—assertions not supported by the OMRDD's return visit on October 7, 1993. This visit confirmed that the individual was not capable of self-administration of medication and the staff involved in administration were not trained or certified to do so. This visit also confirmed that the individual has chronic health care needs which he cannot address independently or with limited oversight and guidance—conditions set forth in regulations for all residents of supportive apartments. A review of the Project L.I.F.E. admission and discharge policies reveals no explicit admission criteria.

Additionally, review of the Staff Supervision Meeting minutes, which reportedly document training/instruction given to staff about particular residents, revealed no documentation of training for staff regarding S.B.'s medical conditions, her various medications, nor any discussions on the importance of having daily contact with her. Staff Supervision Meeting minutes dated December 7, 1992 note that S.B. missed two appointments with her physician and request staff to follow up, which they did.

T.R. was admitted into the housing program in April 1989 with Psoriasis and an Eating Disorder and requires an intensive level of supervision on a daily basis, according to October 1, 1992 Medical Information Log entry. Two of T.R.'s Assessment of Self-medication forms (undated) document that his weight, psoriasis and hemorrhoids remain problematic. Additionally, these forms note that T.R. routinely forgets to take his medications and "his depression which manifests itself in (his) doing nothing/his lack of motivation continues to be a problem for T.R." However, the Evaluation/Thirty Day Review prepared by the Executive Director (undated) reports that T.R. has "no severe or chronic health problems." Review of T.R.'s coaching notes finds that contrary to the assessment of his need for intensive daily supervision, T.R. was not seen on a daily basis by housing staff. (Project L.I.F.E. states that he is seen daily by his job coach and this is sufficient.) Although not addressed in his plan of service, T.R. has experienced signs of illness and symptoms of his eating disorder. Specifically,

- A February 8, 1993 note reports, "because T.R. had tended to overeat the past few months, he has been observed to throw up almost daily."
- February 26, 1993 "Still throwing up a lot."
- February 28, 1993 "T.R. nosebleed and head-ache"
- March 7, 1993 "Complaining of foot hurting."

Project L.I.F.E. documentation reveals that on February 8, 1993 staff called T.R.'s mom who advised that he be given Maalox because the vomiting stemmed from overeating. The notes further state that the physician said "his stomach was OK."

It is unclear from the notes whether T.R. saw the physician. It is clear, however, that his plan of service does not address his eating problems.

Although N.G. has a history of seizures and takes Dilantin (an anticonvulsant medication) daily, his Annual Service Plan Review dated May 6, 1992, fails to note his seizure disorder.

S.N. was admitted on May 21, 1990. His record contains a note dated February 16, 1993 documenting a staff member's discussion with S.N. regarding his need to have the PARS form (Physician's Authorization for Rehabilitative Services) completed by his doctor. S.N. "requested assistance in locating a physician since he doesn't have one."

This suggests that Project L.I.F.E. had not ensured that these individuals had received a medical exam in several years. The Project L.I.F.E. policy manual states that the agency is to inform every resident that he/she is to have an annual medical examination and to submit a copy of the report to the agency. Residents are to be referred to community based health care facilities if they do not have a physician.

Supervision of Residents

Review of the Staff Supervision Meeting minutes revealed several notations regarding staff's concerns about what they perceived as abusive or dangerous living situations, as illustrated below. In several situations, because of the absence of notes, reviewers could not determine what actions staff took to address these situations. In other instances, actions were not timely. Several of the situations represent clear violations of the agency's policy which requires permission from the Executive Director, Associate Director and Housing Coordinator before a "guest" may live in the apartment. One of these situations was clearly abusive; others raise the question of whether the Project L.I.F.E. resident was being exploited.

On December 16, 1992 it was reported in Supervision Meeting minutes that the Management Company had called the agency complaining that a man from K.S.'s apartment (name of "C") was in the lobby. "He smokes crack, is a hustler and has

probably had contact with sexually transmitted diseases," the minutes state.

On December 23, 1992 it was noted that "A guy is sleeping in K.S.'s apartment, he was seen three times". December 30, 1992 meeting minutes report "Bob met with him [K.S.] and he got mad. He [K.S.] spoke to [Field Supervisor] about being afraid to tell this guy to leave. The building is still complaining. This is a police matter. [Coach] will follow up. [K.S.] risking apartment." A subsequent note on February 1, 1993 reports that an "Order of Protection will start as soon as K.S. goes to the police. [Consulting Psychologist] to set up meeting." On March 9, 1993 the "guest" was to meet with K.S. at a Dispute Resolution Center to answer a charge of harassment and interpersonal dispute.

The Project L.I.F.E. listing of Rights and Responsibilities signed by each resident who enters the program addresses the issue of visitors in the following way:

- All visitors will leave apartments by 10:00 p.m., Monday-Thursday nights and Sunday.
- One sleep-over guest on Friday and Saturday nights is permitted.
- Guests are not to come over when residents are meeting with their Housing Coach.
- No one else can live in the Supportive Apartment without permission from the Executive Director, Associate Executive Director and Housing Coordinator.
- Should anything in the apartment be damaged, destroyed, or stolen by a guest, the resident will be responsible for the replacement or repair of the item.

These rules are explicit and reflect an under-

standing that persons with mental disabilities may be unable to protect themselves or their property from unwelcome or irresponsible guests. Yet, there is no documentation that the administration of Project L.I.F.E. took any action to enforce its own policy and to protect K.S. Two months later the agency assisted K.S. in settling the problem with this man, but apparently administrators never confronted the man with his violation of their rules and demanded that he leave.

Similarly, a December 30, 1992 note states that "S.C. has a friend staying there. Possible abusive situation." On February 1, 1993 it is reported "S.C. is a concern, "Fred" (S.C.'s friend) has been beating S.C." On March 29, 1993 it is noted that "S.C. wants [Field Supervisor] to make a home visit. He is having a problem with his friend Fred. He spoke to [coach] about this." Further notes document that the Field Supervisor spoke with S.C. who denied there was any problem between him and his friend.

The discrepant notes leave it unclear whether S.C. was having difficulties with his live-in friend and possibly being abused. There was however no documentation provided that Project L.I.F.E. fulfilled its responsibility to determine that the live-in arrangement was appropriate and had given permission for it as required by agency policy.¹¹

June 10, 1992 Staff Supervision Meeting minutes note: E.C. - "[Coach] senses that his (E.C.'s) thoughts are getting more wild. [Associate Director] emphasized his need to eat. There are papers, labels all over the place—cigarettes, pipes, burn marks on rugs. It is a "fire hazard." In questioning Project L.I.F.E.'s response, their administrators contended that E.C. had never started a fire, and there was no real danger. They also noted that E.C.

The Commission is currently investigating the death of a Project L.I.F.E. resident who on the night of November 2, 1993 sustained fatal head injuries while on the street near his residence. The Medical Review Board, a group of physicians which reviews unusual deaths for the Commission, has determined that the death was most likely caused by a fall and not by a blow to the head. Preliminary record reviews and interviews indicate that individuals, who allegedly engaged in prostitution and possible illegal drug activities, were allowed to stay in this resident's apartment. It also appears that the agency had knowledge of this for several months and took no action until October 29, 1993. On that day, the Associate Executive Director sent the resident a letter informing him that the agency must limit his guests to family members and other Project L.I.F.E. residents.

had been referred for a psychiatric assessment in April 1992, however, no documentation was provided that this service was ever secured. Information received from Project L.I.F.E. in February 1994 indicated that E.C. was hospitalized in the mental health unit of Jacobi Hospital on September 15, 1993, 15 months later, for one month. He was prescribed Prolixin, an antipsychotic medication.

Commission staff visited the apartment below one occupied by resident H.T. This apartment is occupied by a man and his medically frail, bedridden father. The ceiling in the bathroom had been ruined because H.T., as reported to CQC by a Project L.I.F.E. administrator, regularly overflows the bathtub. Because H.T. reportedly frequently and forcefully bangs his furniture against the floor, the ceiling in other rooms of the apartment below is falling in.

Reading the housing notes for H.T. in sequence from the fall of 1991 to the spring of 1993, one cannot help but be struck by how frequently the same issues—distrust, anger, relationship building, reconciliation—repeat themselves cyclicly, without resolution.

The man had moved his dad's bed and furniture to one side of the room to protect him from falling plaster.

When questioned why H.T. was allowed to continue this kind of behavior, several Project L.I.F.E. staff noted that he only rarely allows coaches into his apartment; therefore they cannot intervene effectively. This information is confirmed by various coaching notes, including notes from the fall of 1992 when H.T. would not allow coaches into his apartment for weeks.

Review of several years of notes from various housing coaches revealed H.T.'s considerable difficulty in getting along with coaches and neighbors. This information is consistent with the current and past clinical assessments in his record. These notes also detail behaviors that could have caused and/or

exacerbated the damage to the apartment below. At the same time, the record indicates that many of the apartments rented by Project L.I.F.E. at that address had plumbing problems, suggesting the need for major repairs. There is also evidence that H.T.'s failure to cooperate with those doing repairs (including refusing them access to the apartment) coupled with the clear disdain for H.T., evident in the reported actions of the superintendent of the building and the downstairs neighbor, made a difficult situation even worse.

There is no plan on how to help H.T. Indeed, on the anniversary of his first year in the Project L.I.F.E. housing program, the annual review of his plan of service notes no specific needs for H.T. It notes only that "coaches will make themselves available for [H.T.] and not "push" their services." During that first year and in subsequent ones. coaches regularly rotated through H.T.'s life, each spending varying amounts of time trying to earn his trust—sometimes even to the point of lying to him about their affiliation with the program. Reading the housing notes for H.T. in sequence from the fall of 1991 to the spring of 1993, one cannot help but be struck by how frequently the same issues—distrust, anger, relationship building, reconciliation—repeat themselves cyclicly, without resolution.

Overall Environmental Conditions

Commission staff found environmental deficiencies in each of the 16 apartments they visited. Examples include roaches (3A), holes in ceilings, no curtains, window shades broken in the down position, broken lamps, broken kitchen cabinet doors, windows without screens and windows which would not stay open (4H). Wood rot in window sills and floor boards, chipping paint on walls and doors (4H), shower curtain rods out of the ceiling brackets (1F), and water-stained walls (2M) were also observed.

Approximately 21 of the 60 apartments are rented by Project L.I.F.E., and the landlord is responsible for reasonable repairs. The superintendent in the Crueger Avenue apartment complex

reported that Project L.I.F.E. refuses to make repairs that are caused by the residents and/or to supply coaches to accompany him into the residents' apartments so that he can make repairs. Project L.I.F.E. contends that they will provide coaches to facilitate access to the apartments of residents who are wary of the repairmen, but they cannot afford to have coaches remain while repairs are completed. Thus, Project L.I.F.E. administrators conclude that the failure of the landlord to make repairs and some of the choices made by tenants (such as not to use window coverings) contribute to these environmental deficiencies.

At the time of both reviews, every Project L.I.F.E. resident who spoke to CQC staff reported that the *night before* the CQC announced visits, coaches had cleaned their apartments.

Personal Allowances/Food Monies Distribution

As noted at the beginning of this report, some of the initial allegations made against Project L.I.F.E. concerned the agency's alleged practice of withholding portions of residents' food and/or personal allowances as payment for late rent or other bills. To review these matters, CQC fiscal auditors conducted a limited review of the handling of resident weekly allowances. In a letter dated January 25, 1994, CQC reported the following findings to the agency's Board of Directors with a copy to the OMRDD.

Food/Laundry Allowance

At Project L.I.F.E., residents "retain" their income for the purchase of food and laundry services through weekly cash allowances from the agency. For fiscal year 1991-92, each resident received weekly cash allowances of \$55.00, totaling approximately \$4,000 weekly. Annually approximately \$200,000 or about 10 percent of the agency's budget is remitted to residents for food and laundry services.

The Commission's fiscal review found that Project L.I.F.E.'s internal control procedures did not provide adequate assurances that residents actually received their funds. When a check was drawn for the weekly amount, the cash was turned over by Project L.I.F.E.'s housing coordinator to client counselors who required the client to sign a weekly "cash receipt." However, COC's review of cash receipts over a four-week sample period found that only about 23 percent of the clients were signing for their allowances. While the Commission found no evidence that residents did not receive their weekly allowances, given the volume of cash transactions, there is the inherent danger that funds could be misappropriated unless the agency effectively monitors its system for handling these cash funds.

Project L.I.F.E.'s controller agrees with the Commission's 23-percent figure but argued that if residents had not received their weekly allowances, they would have immediately complained. The Commission is concerned, however, about Project L.I.F.E.'s overreliance on complaints by residents as an effective internal control procedure.

Personal Needs Allowances

OMRDD regulation [14NYCRR 633.99(m) (1)] sets forth the methodology for determining a resident's personal allowance eligibility taking into account the countable (earned or unearned) income. The Commission selected 13 clients to determine compliance with the regulations. It found in each case Project L.I.F.E. was calculating the proper personal needs allowances. Furthermore, from a review of the agency's general ledger and supporting documentation, it appears that payments were properly made to the clients.

The Commission's fiscal review found that Project L.I.F.E.'s internal control procedures did not provide adequate assurances that residents actually received their funds.

Conclusion and Recommendations

The Commission's reviews at Project L.I.F.E. raise serious questions about the management of the program, the suitability of some of the residents for this treatment model, the ability of staff to assess the seriousness of situations and take appropriate action, and the provision of skill training to the residents.

The regulations governing supportive community residences acknowledge the inevitable tension in providing "sufficient oversight and guidance to ensure the health, safety and welfare" of residents while "providing a residential environment that approximates an independent living situation." The Commission recognizes that when an agency juggles the need to protect and guide residents with the obligation to respect their wishes and choices, the path will not be smooth. Growth is not evenly paced, propitiously timed or painless for any human being. Agencies which choose to provide service to persons with developmental disabilities must, nonetheless, take reasonable measures to provide for the safety and welfare of the residents as required under law and regulations.

The Commission's reviews at Project L.I.F.E. raise serious questions about the management of the program, the suitability of some of the residents for this treatment model, the ability of staff to assess the seriousness of situations and take appropriate action, and the provision of skill training to the residents.

Program Management

Some of the program management deficiencies revealed during the review of Project L.I.F.E. are likely the result of the rapid growth experienced by the agency and its failure to devise management/ supervisory structures and procedures to accommodate the increased workload. Informal record-keeping and communication practices, persons carrying essential information "in their heads" and the lack of written policies may not have been problematic when the agency was smaller. Now that the agency runs three different programs at multiple sites, rotating housing coaches every three months, these practices no longer provide sufficient protections for residents. The problematic practices noted in this report included the following:

- absence of admission criteria:
- failure to follow discharge policy;
- failure to follow incident reporting regulations and agency policy;
- failure to put in writing the agency's policy regarding the notification of police in emergency situations;
- failure to implement a formal process for the transmission of medical information to staff who have a need to know:
- failure by supervisors and administrators to develop a process for the review of case notes and meeting minutes which ensures that they are accurate; and,
- failure to focus treatment planning around the most critical needs of residents—needs which often lay beyond apartment cleaning and grocery shopping or cooking.

Suitability of Some Residents

It is clear through the CQC review and from OMRDD certification reports that several residents have physical and mental health needs that are not being addressed and which are serious enough to place them at risk. The failure of the agency to conduct objective and accurate annual assessments of each resident's ability to self-medicate has led to some of these problems.

Staff Competence and Training

The numerous erroneous record entries by staff members and the absence of correction by supervisory staff who counter-signed them suggest that some coaches are ill-equipped to deal with the often significant needs of residents. While these staff may be perfectly competent to teach the activities of daily living in the community, i.e. budgeting, cooking, cleaning an apartment to persons who are cooperative with the coaching, notes repeatedly reveal that many residents are resistant, and coaches are unable to deal with this effectively. While weekly supervisory sessions are held and are undoubtedly useful, more formal supervisory structures are needed to ensure that coaches understand the strengths and needs of the residents to whom they are assigned and have specific strategies for dealing with common problems.

The failure of the agency to ensure that its staff were trained in medication administration was particularly problematic, especially when coupled with the inaccurate assessments of the ability of some residents to administer their own medication.

We understand that the OMRDD shares our concerns and has been taking measures to correct many of the deficiencies.

Recommendations

In order to ensure the safety of particularly vulnerable residents at Project L.I.F.E., the Commission recommends that:

(a) The OMRDD, in conjunction with Project L.I.F.E., evaluate the suitability of each of the Project L.I.F.E. residents for a supportive community residence and the ability of Project L.I.F.E. to

provide residents supervision and monitoring commensurate with their needs as demonstrated by their present circumstances.

- (b) Project L.I.F.E. must ensure that all of the residents' health needs are skillfully assessed and addressed. These health screenings should contain a mental health component where this seems necessary, as it appears from the behaviors of some of the residents that they have unmet mental health needs.
- (c) The provision of vocational assessments on those individuals who have no constructive daytime activities should be a priority. We are unable to determine how many individuals this may involve as the information provided on-site and information provided later by Project L.I.F.E. differ significantly on the number of residents who work and/or attend school or another day program.
- (d) The obligation to safeguard the welfare of residents extends beyond effective program planning and resident monitoring and supervision to the development and implementation of systematic procedures for reporting, investigating and reviewing incidents. The Commission's review raised serious questions regarding the agency's performance of this function, particularly in view of the dearth of information in the IRC minutes and the stated philosophy of the agency to minimize documentation of residents' difficulties.

The Commission therefore recommends that the OMRDD evaluate the ability of the facility to discharge its obligations under the incident reporting regulations (14 NYCRR 624) and provide technical assistance as necessary.

- (e) Project L.I.F.E. clean and repair apartments and furnishings as necessary and ensure that agency personnel are available to escort maintenance staff, as needed, into those apartments rented from other landlords.
- (f) The OMRDD ensure that Project L.I.F.E. develops and implements a quality assurance plan. This plan needs to address the agency's compliance with regulations and ensure that sound and accountable management practices are in place.

Appendix A

75 MORTON STREET, NEW YORK, NY 10014-5798

ELIN M. HOWE Commissioner THOMAS A. MAUL Executive Deputy Commissioner

February 11,1993

Dr. Anita Schwartz
Executive Director
Project L.I.F.E., Inc.
North Academic Complex Room 3/226
138th St. and Amsterdam Avenue
New York, New York 10031

Dear Dr. Schwartz:

I am herewith forwarding to you the enclosed report of the management review of Project L.LF.E., Inc. conducted by staff from the New York City Regional Office. I believe this report reflects the findings and recommendations which were informally shared with you and your staff at the time of the review.

May I request that you review the findings and recommendations and forward to me within 30 days your response to this report. You are free to express either acceptance or disagreement with the findings and recommendations. I would ask that if you disagree with any part of the report that you specify your reasons.

In reference to the recommendations which are acceptable I would ask that you indicate whether or not a recommendation is already implemented or will be implemented with an indication of the time frame for completion of the recommended action.

Thank you for your cooperation. If you have any questions please contact John Sabatos at (212) 229-3257.

Sincepely

James M. Walsh

Associate Commissioner

JMW/cmc

encl.



Being retarded never stopped anyone from being a good neighbor.

REPORT ON MANAGEMENT REVIEW OF PROJECT L.I.F.E., INC. PERFORMED BY THE NEW YORK CITY REGIONAL OFFICE OF N.Y.S.O.M.R.D.D.

I - INTRODUCTION

1. Scope and Intent

NYCRO performed a limited management review of Project L.I.F.E.,Inc.using as a guide the standards and interpretative guidelines of "The Accreditation Council on Services for People with Developmental Disabilities" (1990 Edition - Landover, Md.) The intent of the review was to determine whether the agency's policies and procedures are implemented using management systems and practices which ensure effective and quality services to the people served by the agency. Project L.I.F.E., Inc. has a limited focus in its service delivery system encompassing supported employment, supported housing and comprehensive medicaid case management. A limited number of standards judged to be consistent with the agency's service delivery system were selected from the Accreditation Council Guideline.

2. Methodology

Reviewers interviewed administrative staff (executive director, associate executive director, employment and housing directors and the fiscal director), job and housing coaches and program participants. Interviews were conducted using Accreditation Standards as a guideline. The agency policy procedure manual, operations manual, personnel manual and other documents such as meeting minutes and fiscal records were reviewed for verification of practices. A 10% sample of participants records was also reviewed to determine the continuity of management practices and quality services.

Results of these interviews and record/document reviews were then categorized into FINDINGS

AND RECOMMENDATIONS which are outlined in Part II of this report.

3. Date and Location

The review was conducted on October 13,14 & 15, 1992 at the administrative offices of Project L.I.F.E. and at 9 Apartments located at 125 W. 96 St, Manhattan; 2195 Bolton St., Bronx; 2178 Cruger St., Bronx and 2077 Wallace Ave., Bronx.

4. Entrance Conference

The review opened with an Entrance Conference at the administrative offices. Executive staff gave an overview presentation of the agency's founding in 1986 through its development to the present status of operations. The presentation was thorough and included printed descriptive material outlining the agency mission, operations and organizational structure. The agency presentation concluded with a video presentation of network television coverage on various occasions featuring the agency.

The NYCRO program/management reviewers, John Sabatos and Darlton Haskins explained the scope and intent of the review (see No. 1 above) emphasizing that this review was meant to be positive. The intent is to offer recommendations which will help improve management policy and practices. The reviewers noted that this exercise was not an audit against certification standards.

II . FINDINGS AND RECOMMENDATIONS:

1) Consumer Empowerment and Decision making

Findings:

The consumer is involved in choosing employment and housing. At intake the consumer is provided with a full written client's rights statement. Signatures indicating it has been received are required. Consumers reported ongoing communication with staff and family so that they could express their desires. Consumers expressed satisfaction with staff in that they were able to communicate desires and needs quite readily.

Although consumers indicated involvement in making choices and decisions were very demonstrative in support of the agency's openness in this regard there is no formal statement in the policies and procedures manual in this regard. The "Project L.I.F.E. in a Nutshell" description of the "In House Expression" and "Empowerment" sections are an excellent basis for a formal statement. These sections demonstrate clearly the agency belief in empowerment and decision making.

Recommendation:

Include a written statement in the policy procedure manual concerning consumer empowerment and decision making in such areas as place of residence and employment, relationships and daily living routines.

2. Habilitation and Support Services

Findings:

A random sample of seven participants' records was made during this review. The sample included participants who are involved in one or more of the agency's programs. Project L.I.F.E. has individualized records for each participant enrolled in its Housing, Employment and CMCM programs. As explained by one of the agency's representatives, the various funding sources utilized and the specific reporting requirements preclude their use of an integrated record keeping system. Anecdotal notes from the coach/case manager are found in the records as the means or verification of contact with the participant. Several of the records do not contain current case notes to indicate whether the participant is receiving active intervention from the program. Notations made by the coach/case manager indicate concerns either voiced by the participant, raised in discussion or observed are noted without indication of closure. The records of those person's involved in the Housing program are extremely scant with limited information relative to admission, initial planning, assessment of need, annual reevaluation, program planning and revision. Based on the uniqueness of the population served by the agency, agency mission and philosophy, traditional modes of evaluation and planning are superseded by other coordinative means keeping the participant as the locus of positive outcome.

It should be noted that all of the coaches notes are read weekly by the Executive Director who in turn makes inquiries of the Directors of the Housing and Employment programs for follow-up. Written feedback is provided to the Executive Director by the incumbents vis a vis the "wind-up" meetings and ongoing dialogue between staff members. Though all records do not contain current

case notes there is a timely, effective and preventative system in place to address the concerns highlighted in the filed notes.

Recommendations:

Based on the findings in the area of client records, there is a need for additional administrative support services to aid the agency in providing a wholistic clinical picture of the individual and the interventions provided to assess their effectiveness or need for revision.

3. Family Supports

- Findings:

Administrative staff and coaches indicate that there is contact with family members of program participants. Participants also told us of contacts with parents and siblings. For example, participants invite family members to their apartments for meals or go back home on visits However, administrative staff openly admitted that family members are not routinely invited to participate in annual plan meetings or even periodic reviews. Family is contacted in cases of emergency but there does not seem to be a formalized process to have family members attend case reviews or annuals or receive regular progress reports. Once again, the outline "...in a Nutshell" indicates that the agency supports family empowerment in general terms of encouraging participation and meeting attendance.

Recommendation:

Revise policies and procedures to specifically state that family members are to be invited to be a part of annuals and goal plan reviews. Institute a procedure for notification of families and record the family response. Have a written policy on regular family involvement and notifications of participant progress.

4. Human Rights Committee

Findings:

The agency Policy and Procedure manual has sections dealing with incidents, abuse and investigations. However, there is no stipulation for the formation of a human right's committee to review these matters and other concerns for human rights of the individuals served by the agency.

Recommendation:

Include a written policy on a human right's committee and establish such a committee.

5. Financial Interests of Each Individual

Findings:

Although some individuals maintain their own account, by and large, all the funds of each person served are placed in one agency account with individual ledger cards maintained to track each persons funds. There are no formal written agreements between the agency and each individual on

fund management. There are only verbal agreements. The fiscal officer gave indication that individual accounts for each person were in the process of being established by the agency.

Recommendation:

Have a formal written policy on agreements and management of funds for each person. Complete the process of establishing individual interest bearing accounts.

7. Agency Self Evaluation

Findings:

Staff members meet annually on a two day retreat in order to assess progress of the agency towards its mission and goals. This practice is commendable and has resulted in setting goals for the continued growth and commitment of the agency and staff to quality services. The record of evaluation and goal setting from these retreats is kept in a variety of notes recorded by staff members.

Recommendation:

The agency should formally document the annual evaluation and goal setting process in a separate written record. This will provide a benchmark for each successive year's evaluation and goal setting process.

8. Governing Body

Findings:

The board of director minutes and agendas for 1991 and 1992 were reviewed. The minutes revealed that the agendas covered budget, staffing, fund raising, housing issues, recreation programs, etc. Generally the by laws and policy statements on the function of the governing body were in conformity with recommended standards in the OMRDD manual on the function of a governing body. Some information was lacking such as an updated table of organization, lack of fiscal management policy and lack of evidence that the board receives and reviews certification surveys.

Recommendation:

It is recommended that the board maintain an updated table of organization, have a fiscal management policy (which includes: review of a annual budget, procedures for reviewing ongoing fiscal status of the agency, procedures for dealing with fiscal irregularities and problems. The board should also have a procedure for periodic update on the status of certification reviews.

Appendix B

STATE OF NEW YORK OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NY • 12229-0001 518-473-1997 518-474-3694 TDD

THOMAS A. MAUL

June 3, 1994

ULUSS THOMPSON Executive Deputy 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 12210-2895

Dear Mr. Sundram:

OMRDD staff have reviewed the Commission's draft report of Project Life. It is noted that many of your findings are consistent with the findings of our surveys.

A hearing on the discharge of one resident has confirmed that Project Life acted in violation of the regulations in the discharge of A.J. Project Life has acknowledged its failure and has submitted a plan of correction which OMRDD has accepted. We are monitoring adherence to its plan of correction.

OMRDD's surveys conducted in 1993 identified problems with Project Life's adherence to the regulatory requirements regarding incident reporting. Serious problems have also been identified in the areas of supervision and administration of medications, medical care and coordination, provision of day programs for individuals, and program planning appropriate to meet individual needs.

Many of the recommendations made in your report have been initiated. A review of the suitability of the current individuals residing in apartments operated by Project Life was conducted by the Bronx DDSO and New York City Regional Office in December 1993. OMRDD staff have been seeking sources of services for those individuals who were identified as needing additional services.

The results of these surveys are being considered and a decision on what action OMRDD will take to ensure that the services provided by Project Life are consistent with the requirements of Mental Hygiene Law and regulations is imminent.

Thomas J. Cuite

Deputy Commissioner

Division of Quality Assurance

Appendix C

The following are corrective measures which Project L.I.F.E. reports to the Commission that it has taken since the Commission's initial contact with the agency in September 1992:

- The housing coaches no longer rotate sites. There are three tiers of staff levels. The Residential Habilitation Service Coordinator serves as the immediate on-site Supervisor. This person is also referred to as Team Leader. Directly underneath is the Residential Habilitation Skills Worker Level I and Level II.
- In addition to the structure described above, the agency employs three nurses. Nursing coverage is as follows: M F 8am 1pm and 5pm 10pm; Saturday and Sunday 9am 6pm. The nursing staff communicate all medical information to staff who have a need to know it as well as to the Case Management Director and Housing Director at a weekly windup. The implementation of the nursing staff has decreased the need for staff to be involved with medication administration.
- The Housing Program Director has a part-time support person to do the filing and to keep the housing data base up to date.
- ♦ The agency is in the process of centralizing the

- records of the program participants.
- The agency has expanded and now ample space to work.
- Admission criteria are clearly stated in the Agency's Policy and Procedure Manual and is adhered to. All individuals currently in the supported apartment program met this criteria at the time of admittance to the program. Some of these individuals due to aging, medical conditions or behavioral problems have deteriorated and if they were applying for admission today would be referred to more suitable residential settings. These individuals have had applications for additional services submitted to OMRDD/CSEP on their behalf.
- The agency assesses all incidents reported by participants, staff, parents, community members, etc. After an investigation the agency makes reasonable judgment as to what incidents are reportable. All reportable incidents are reported in compliance with OMRDD regulations.
- Supervisors and Administrators meet weekly to review case notes and all issues regarding program participants. These meetings are carefully documented.
- With technical assistance from OMRDD, the agency has enhanced its understanding of the need for treatment plans to focus on all aspects of the individual's life. Long-term and short-term goals are established with

defined time frames to assess progress.

- The Agency provides support services commensurate with each individual's needs. The Agency's systemic measures ensures that there is an adequate level of support service 24 hours daily, 7 days per week, 365 (or 366) days per year. These are:
 - (1) Actual on-site coverage from 8am to 10pm daily;
 - (2) Actual on-site coverage on weekends;
 - (3) All housing staff (including the Housing Director) are equipped with beepers:
 - (4) 24 hours daily beeper coverage (which includes a person who covers from 8pm to 8am in order to ensure round-the-clock coverage);
 - (5) Administration is on call 24 hours daily; and
 - (6) Actual on-site holiday coverage.

In addition to citing the corrective measures noted, the Project L.I.F.E. response concludes with a call for additional funding for "administrative support staff in order to improve the quality of the case records." In addition the agency needs funding and technical assistance to establish a computer program and network system which will allow access to all components of the case records. Finally, additional funding is needed to provide enhanced educational and recreational opportunities for the residents.