



# **FAMILY CARE FOR THE MENTALLY ILL: THE UNFULFILLED PROMISE**

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

**October 1979**

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EXECUTIVE SUMMARY

The family care program administered by the Office of Mental Health is a significant part of its efforts to place psychiatric patients in a less restrictive environment than provided by the psychiatric hospital.\*

A public hearing conducted by the Commission in Buffalo last October elicited community concern about the family care program operated by Buffalo Psychiatric Center, the largest such program run by a psychiatric center in the State.\*\* This hearing and others held by the Commission resulted in family care being targeted as one of the 12 areas for particular attention.

In January 1979, the family care program was the subject of a series of local newspaper articles in Buffalo. In response, Commissioner James Prevost requested the Commission to examine the management and operation of the family care program run by Buffalo Psychiatric Center.

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\*Over 3,000 persons reside in OMH licensed family care homes while just over 1,300 persons are served in OMH licensed community residences. New York State Office of Mental Health, Annual Report on Community Residents 5 (March 1, 1979).

\*\*Buffalo Psychiatric Center has over 460 family care residents, and St. Lawrence Psychiatric Center serves over 430 family care clients. There are only four other psychiatric centers with a family care population of 200-300 persons, while five facilities serve between 100-199 family care residents. Twenty-five psychiatric centers have less than 100 persons in family care. Letter from Angela Zeppe-tello, Federal Program Coordinator of the Bureau of Patient Resources of the Office of Mental Health to Walter Saurack of the New York State Commission on Quality of Care for the Mentally Disabled (February 22, 1979).

The Commission agreed to do so as part of a larger Commission effort to examine the family care program state-wide. This report represents an assessment of the family care program at Buffalo Psychiatric Center as it existed during the period of January through March, 1979.

As an evaluative effort designed to assist the Office of Mental Health and Buffalo Psychiatric Center improve the family care program, this report, of necessity, emphasizes the deficiencies in the program. However, as we attempt to point out in the body of the report, we witnessed several individual homes that epitomize the highest expectations of the program.

In conducting this study, Commission staff selected 25 homes at random for the review. Commission staff performed a comprehensive review of the Buffalo Psychiatric Center records on the selected homes and examined records of a total of 47 clients prior to site visits and interviews. Day programs in which clients participated were visited and the clients and program staff were interviewed. In addition, staff from the Buffalo Psychiatric Center and the Office of Mental Health Regional Office responsible for the administration of the family care program and for ensuring the continuity and adequacy of care for the clients were interviewed. The Commission spent approximately 75 staff days in the field conducting this study.

Findings

FIRST, THE REALITY OF FAMILY CARE DIFFERS SIGNIFICANTLY FROM THE CONCEPT PROPOUNDED BY THE OFFICE OF MENTAL HEALTH OF A TRANSITIONAL STEP IN THE CONTINUUM FROM INSTITUTION TO INDEPENDENT LIVING. THE PROGRAM IS NOT TRANSITIONAL BUT A DEAD END FOR THE MAJORITY OF PATIENTS PLACED IN FAMILY CARE (Report, pp. 4-6).

A. The family care program at Buffalo Psychiatric Center serves primarily elderly patients with a long history of psychiatric hospitalization. Both as a result of the type of patients predominantly placed in family care and because of the lack of other community placement alternatives in the Buffalo Psychiatric Center catchment area, the family care program is the first and final stop for many deinstitutionalized patients.

B. The family care providers do not perceive their role as preparing the client for more independent living even where this is a realistic possibility. Indeed, they resent and resist removal, from the home, of a patient whose level of functioning indicates a readiness for a less restrictive environment. The discharge of such a patient is often viewed as punishment for having succeeded in enabling the client to progress.

SECOND, WITH OCCASIONAL EXCEPTIONS, THE FAMILY CARE HOMES DO NOT PROVIDE THE THERAPEUTIC/REHABILITATIVE ENVIRONMENT ENVISIONED BY THE OFFICE OF MENTAL HEALTH (Report, pp. 51-61).

A. Clients are often physically and socially isolated in the household and live in worse conditions than the rest of the provider's family. Separate but unequal is all too true and common in family care (Report, pp. 51-55).

B. Medication storage and dispensing practices are dangerously out of compliance with OMH standards (Report, pp. 58-61).

C. Although 18 of the 25 homes in the sample were in reasonable compliance with fire safety standards, there were deficiencies. Fire drills were rare and in some homes fire extinguishers, required by regulations to be on the premises, were either not readily accessible or providers did not know how to use them (Report, pp. 56-58).

D. Physical and sanitary conditions of several of the homes need major improvements (Report, pp. 54-55).

E. There was no pattern of abuse and mistreatment found in the sample of homes reviewed, although the residents in one home were assigned tasks not shared by other family members (Report, p. 46).

F. In a few homes, the clients and providers had managed to build up close, supportive, family-type relationships (Report, p. 54).

THIRD, THERE ARE MAJOR DEFICIENCIES IN THE ADMINISTRATION AND PROVISION OF MEDICAL CARE AND SERVICES TO CLIENTS IN FAMILY CARE RESULTING IN INADEQUATE, IMPROPER AND FRAGMENTED CARE.

A. Most of the family care providers were inadequately trained in medication storage and dispensing and in monitoring the effects of the medications (Report, pp. 60-61).

B. This deficiency is compounded by OMH policy, which does not require physicians to review periodically the medications the client is receiving or the progress being made by the client under medication. In addition, physicians at Buffalo Psychiatric Center showed minimal involvement with their patients (Report, pp. 25-27). Indeed, we discovered that at Buffalo Psychiatric Center, non-physicians had signed monthly medication orders for the clients (Report, p. 27).

C. Annual mental status examinations are required for all patients by OMH policy. However, we found that in 1978 for 35 out of 47 clients in our sample, there were only cursory notes by the psychiatrists, and the remainder lacked psychiatric notes of any kind (Report, pp. 28-29).

D. Where physical examinations of clients were performed annually as required, the results were not communicated to BPC. Thus, BPC staff remained ignorant of changes in the clients' physical condition which often resulted in residents not obtaining necessary follow-up medical care (Report, p. 28).

FOURTH, IT WAS EVIDENT THAT BUFFALO PSYCHIATRIC CENTER STAFF DID NOT PLAY AN ACTIVE ROLE IN THE TREATMENT OF CLIENTS IN FAMILY CARE EVEN THOUGH THE CLIENTS CONTINUED TO REMAIN ON THE PATIENT ROLL OF THE CENTER.

A. The lack of treatment to family care clients was made apparent to Commission staff members through their interviews with patients, family care providers, family care teams and staff in day programs. This lack of treatment was reflected in the client records. There were gross deficiencies in the use of the form called the Individual Service Plan which made it clear that this document, intended as a blueprint for services to be rendered, was instead being perceived as a paper requirement. As a result there was insufficient thought given to each patient's needs (Report, pp. 8-10).

B. There was no evidence of any intention to implement such individual service plans (Report, pp. 10-12).

FIFTH, THE FAMILY CARE PROGRAM IS POORLY ADMINISTERED AND THERE ARE SHORTAGES IN CLINICAL STAFF.

A. There is excessive reliance upon family care as an alternative to the institution. This is partly due to the lack of other forms of community placement which deprives the facility of other options and makes it impossible to routinely match clients and providers. Instead, BPC is forced to consider where vacant "beds" are available, with the clients' needs of secondary importance (Report, p. 10).

B. The administration of family care was decentralized and there were wide variations in performance among the geographic units. This, along with inadequate central

management by the facility, resulted in a lack of cohesiveness in the program. For example, some units were in complete compliance with the required monthly visits and other units were not. In some units staff members would make special efforts to settle a patient in a new home while others did not visit the home at all during the first few weeks (Report, pp. 17-20).

C. We found no systematic effort to evaluate the quality or effectiveness of the family care homes. There were few unannounced visits to family care homes by BPC staff, and such visits as were made did not result in deficiencies in the homes either being noted or corrected. Even when visits were made, the reports were cursory and uninformative (Report, pp. 20-24).

D. The Regional Office played an insignificant role in monitoring both the family care homes and BPC. The Regional Office delegated most of its oversight functions to the psychiatric center itself. In effect, this resulted in the staff responsible for providing services to the family care homes monitoring their own performance (Report, pp. 78-81).

E. We found that BPC relied excessively on mental hygiene therapy aides to perform diverse clinical and administrative functions. The responsibilities assumed by these persons conflict with the job classification standards for such positions as established by the Department of Civil Service (Report, pp. 32-33).

SIXTH, THERE IS AN OVERALL LACK OF COMMUNICATION AND COORDINATION AMONG BUFFALO PSYCHIATRIC CENTER STAFF, FAMILY CARE PROVIDERS, COMMUNITY AGENCIES PROVIDING PROGRAMS FOR THE CLIENTS AND THE CLIENTS THEMSELVES. SERVICES ARE PROVIDED IN PIECEMEAL FASHION AND THERE IS NO CONTINUITY OF CARE FOR THE PATIENT (Report, pp. 12-14).

#### Conclusions and Recommendations

Family care is an important part of the State mental health system. Family care providers serve as a valuable resource in providing economical lodging and boarding in a less restrictive environment than a State institution. However, many of the State's expectations of this program appear to us to be either unduly optimistic or unrealistic.

First, and fundamentally, it is unrealistic in most cases to expect that the delicate and personal relationships within a family will adapt to the addition of new and unfamiliar members, especially persons who are mentally disabled. This is particularly the case given the limited ability of the family care programs at BPC to match clients and providers. That so many of the clients in our sample were segregated from the family is not so much a reflection upon those who provide the care as upon the concept. Part of the reason for the failure of the concept of this simulated family is that there are no readily apparent traditional family roles for an adult mental patient in a family.

Elderly clients may be integrated into a family in the role of a grandparent, but the general tendency is to treat adult clients, who require more attention and supervision than non-clients, as children, creating an environment which differs significantly from normal family life.

Second, just as it is unrealistic to expect integration of most clients into a family, so too it is unrealistic to expect family care providers to act as staff to the psychiatric center and provide skilled care to the clients. This is not intended as a condemnation of the providers, many of whom have both the desire and the ability, if properly trained and supervised, to perform these functions.

Third, it is apparent to us that this program will be unsuccessful in serving its purpose in providing a transition for clients from the hospital to more autonomous living unless there are community placement alternatives offering more independence.

Fourth, even assuming the creation of an integrated network of community placement alternatives that form a continuum of care from the institution to independent living in the community, where appropriate, it seems to us essential to establish incentives for family care providers to help clients reach their full potential, even where it means leaving the home. Such a discharge must be viewed as a success, and rewarded as such, rather than being perceived as a failure for which the provider is penalized either by

(x)

the loss of income or by the burden of integrating a new person into the home. Clearly, such a system of incentives will need close monitoring of the quality of proposed discharges to prevent dumping of clients from family care homes. We therefore recommend:

- (1) THAT THE OFFICE OF MENTAL HEALTH REASSESS ITS EXPECTATIONS OF FAMILY CARE, PARTICULARLY THE ROLE OF THE PROVIDER IN PROVIDING SKILLED CARE TO THE CLIENTS.
- (2) THAT PRIORITY BE GIVEN AT BUFFALO PSYCHIATRIC CENTER TO EXPANDING THE RANGE OF COMMUNITY PLACEMENT ALTERNATIVES.
- (3) THAT THE OFFICE OF MENTAL HEALTH EXAMINE THE FEASIBILITY, PERHAPS ON A DEMONSTRATION BASIS, OF CREATING A SYSTEM OF INCENTIVES FOR FAMILY CARE PROVIDERS FOR PREPARING CLIENTS FOR MORE INDEPENDENT LIVING WHERE THAT IS DEEMED APPROPRIATE.

\* \* \*

The quality of the family care program can best be described as neglectful. To avoid warehousing clients in family care, it is essential that they be given more active treatment. The psychiatric center staff should play a leadership role in ensuring that each client gets needed clinical attention. The Individual Service Plan, if properly utilized, is the key to this process.

Family care teams should have additional professional staff instead of relying on therapy aides to perform administrative and clinical functions. Closer coordination of staff efforts and stronger administration of this program are essential to ensuring that available treatment resources are fully utilized. We therefore recommend:

- (1) THAT THE INDIVIDUAL SERVICE PLANS BE USED AS A REAL PLANNING TOOL AND IMPLEMENTED AS SUCH.
- (2) THAT THE FAMILY CARE TEAMS BE AUGMENTED BY THE ADDITION OF PROFESSIONAL STAFF TO PROVIDE SERVICES TO CLIENTS IN FAMILY CARE.
- (3) THAT THE ADMINISTRATION OF THE FAMILY CARE PROGRAM BE STRENGTHENED TO COORDINATE THE USE OF ALL TREATMENT RESOURCES AVAILABLE WITHIN THE BPC CATCHMENT AREA.

\* \* \*

There is a critical need for much more vigilant regulation of the family care homes than we witnessed during our study. Although the Regional Office is conceptually responsible for regulating the homes, in practice both regulatory and clinical functions are assigned to the treatment units at BPC. This requires the family care teams, in part, to monitor their own performance, resulting in a lack of independent monitoring which permits the conditions we have described to flourish in some homes.

In the course of our investigation, we found no reluctance on the part of providers to comply with regulations when appropriately instructed. It seems clear that the providers would welcome clear guidance on what is expected of their homes. Particular attention is needed in the areas of fire safety and medication storage and dispensing. The Board of Visitors, an independent citizen watchdog body, has no oversight jurisdiction over family care homes. With increasing emphasis on community alternatives to institutions, including community residences and family care homes, it is time to broaden the role of the Board of Visitors.

The Commission recommends:

- (1) THAT THE REGIONAL OFFICE SHOULD PLAY A LARGER ROLE IN THE INSPECTION AND REGULATION OF FAMILY CARE HOMES. IT SHOULD PERIODICALLY ASSESS THE EFFECTIVENESS OF THE PSYCHIATRIC CENTER'S MANAGEMENT AND OPERATION OF THE FAMILY CARE PROGRAM; AND
- (2) THAT LEGISLATION PROPOSED BY GOVERNOR CAREY (S. 6299-A SENATOR PADAVAN; A.8190-A ASSEMBLYWOMAN CONNELLY) TO PROVIDE A MECHANISM TO PERMIT BOARDS OF VISITORS TO VISIT AND INSPECT FAMILY CARE HOMES AND COMMUNITY RESIDENCES BE ENACTED.

As part of the process of strengthening the administration of the family care program, clear responsibility should be placed on medical professionals for overseeing all medical services required by or provided to clients in family care. It is critical that periodic reviews by physicians of patients' medication regimens be instituted to properly monitor the drugs being administered to family care clients. It is essential that the practice of non-physicians signing monthly medication orders cease immediately. There ought to be consistent efforts to obtain from providers their observations on the effect of medication being given to clients. This would be an important factor for the physician to consider before continuing or changing medications. Family care providers will require training to recognize the intended and unintended effects of medications. Beyond training, providers should be given specific information regarding the intended and possible side effects of medications being prescribed for each client.

Responsibility for good medical care should be assumed by the medical and nursing staff of the family care teams. Complete medical information should be available to the physicians prescribing psychotropic medications for their clients. Although outside health services are used by the clients, it is essential for BPC nursing staff to direct, coordinate and monitor the use of these services.

The Commission recommends:

THAT THE RESPONSIBILITIES OF THE MEDICAL AND NURSING STAFF AT BPC SHOULD BE REDEFINED. IT SHOULD BE THE PRIMARY RESPONSIBILITY OF THE NURSING STAFF TO MONITOR AND COORDINATE ALL ASPECTS OF MEDICAL SERVICES TO FAMILY CARE CLIENTS. THE NURSING STAFF SHOULD ALSO BE RESPONSIBLE FOR MAKING THIS INFORMATION AVAILABLE TO THE PHYSICIANS.

\* \* \*

THE COMMISSION, IN CONCLUSION, RECOMMENDS THAT THE OFFICE OF MENTAL HEALTH USE THE FINDINGS AND RECOMMENDATIONS OF THIS REPORT AS A FIRST STEP IN A COMPREHENSIVE STATEWIDE EVALUATION OF FAMILY CARE.

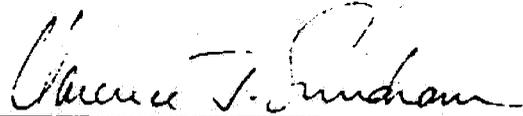
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Many of the observations contained in this summary have been communicated to the administrators at Buffalo Psychiatric Center and to the Commissioner in the course of conducting this investigative review. Some of the deficiencies we have cited have been corrected as indicated in the correspondence appended to this report.

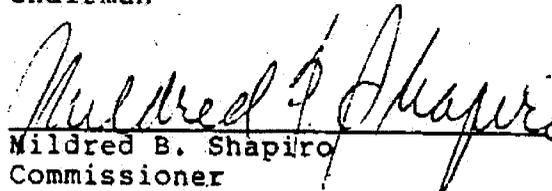
Commissioner Prevost's response to a draft of this report indicates that "we have made some major management changes in our family care and other alternative living programs which have already produced a majority of the changes which both of our staff agree were necessary" (See Appendix A for this response).

The Commission is aware of the effect upon employee morale of a report of the Erie County Grand Jury which studied some aspects of the operation of Buffalo Psychiatric Center. The Commission report is not intended to further demoralize the administration and employees at Buffalo Psychiatric Center, but to serve as a guide to improving the quality of life for patients in family care.

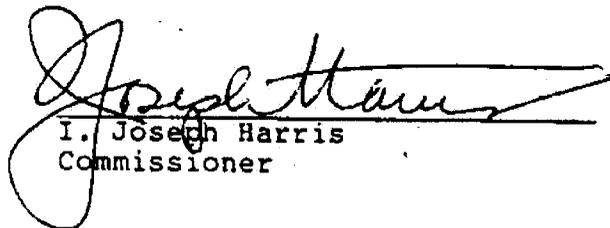
The Commission wishes to acknowledge the cooperation it has received from Commissioner Prevost and from Dr. Ralph Michener, Director of Buffalo Psychiatric Center, and other employees of the facility, in the course of this investigation. We have also enjoyed the advice and assistance of the Board of Visitors of Buffalo Psychiatric Center.



Clarence J. Sundram  
Chairman



Mildred B. Shapiro  
Commissioner



I. Joseph Harris  
Commissioner

INTRODUCTION

This investigative review of the family care program operated by Buffalo Psychiatric Center was undertaken by the Commission upon the request of James A. Prevost, M.D., Commissioner of the State Office of Mental Health. This request followed a series of articles in the Buffalo Evening News which cited serious shortcomings in the family care program.

Commission staff members spent over 75 days in Buffalo in the middle of winter visiting and inspecting family care homes and day programs, and reviewing patient records. They also interviewed patients, BPC staff, Regional Office staff and personnel from the Erie County Department of Mental Health.

The six clinical staff assigned to the study had a total of 64 years experience in working with the institutionalized and deinstitutionalized mentally disabled as psychiatric social workers, rehabilitation counselors, psychiatric nurses and in other clinical or treatment capacities. They were thus uniquely qualified to examine all facets of the operation and management of this program.

AN OVERVIEW OF FAMILY CARE AT BPC

The family care program is designed to provide residential care for persons no longer required to be hospitalized. Individuals in this program receive care and treatment for their particular needs to enhance their ability to function adequately in their own homes or in other community living arrangements. The treatment network for the OMH family care program is composed of three basic units: the family care home, the psychiatric center, and day treatment generally provided by a community-based agency.

1. Family Care Population: A 1979 OMH report on family care and community residences stated that "Family Care has increasingly moved in the direction of providing long-term care for elderly chronic patients."<sup>1</sup> This assessment is supported by the characteristics of the BPC sample population. Although the mean age for residents in the sample was 62 years, nearly one-third of the residents were in their 70's or 80's. In contrast, three persons were in the 35-50 year age range and only one resident was in the 20-35 year category. Most of the clients had been in the family care program for about six years, and had lived generally in one or two family care homes during this period.

The psychiatric histories of the clients in the sample also show that most have been hospitalized for extended

periods of time and suffer from serious mental disorders. Seventy percent of the residents in the sample (33 of 47) have a diagnosis of schizophrenia, while eight other residents have a primary diagnosis of other psychoses, with two diagnosed as being mentally retarded and one of the two also having epilepsy. Of the five clients in the sample with a diagnosis of organic brain syndrome (OBS), two were diagnosed as OBS with psychosis, one as OBS with psychosis and alcoholism, and another as OBS with paranoid ideation. One person in the sample was diagnosed as being in "involutional paranoid state."

Most of the sample population have had psychiatric problems for over 25 years and typically were hospitalized for the first time in their young adulthood (age 30). Of the 47 clients sampled, only one resident had a psychiatric history of less than seven years.

Almost every resident was receiving some form of medication. Forty-three of the forty-seven residents were taking medicine for psychiatric and/or seizure disorders, while 37 clients were prescribed neuroleptics or antipsychotic medications. Seven of these persons took at least one of the neuroleptics by injection. Over half of those persons receiving medications (23 persons) were taking two or more medications, with 17 on an antiparkinsonian drug for the side effects of the neuroleptic medicines.

2. Residential Opportunities: The residents in the family care program at BPC suffer from serious and chronic disabilities which necessitate long-term supervision. The residential services for the mentally disabled available in the Buffalo area are limited essentially to two programs: family care and Transitional Services, Inc. (TSI).

The Transitional Services program provides different levels of care which range from closely supervised living to independent living. All clients in this program are expected to move through these different levels of care in accordance with specific time frames. Clients are not permitted to live in a supervised setting in the program for an indefinite period of time. BPC staff responsible for the placement of clients generally view this program as inappropriate for the vast majority of clients being placed in the community. During the course of interviews, BPC staff cited cases where clients, required to live on their own, stopped taking their medicine and became acutely ill. Within the sample, three family care residents had been in the TSI program and another client had been rejected. All three failed in the program, one due to behavioral problems and a second had become "reclusive and withdrawn" while living alone. The third person who failed in TSI had stayed for five months, but no reason for leaving was found in the client's records. The one person rejected by TSI needed greater supervision than could be provided by the program.

In assessing the appropriateness of placement in family care, the Commission's clinical staff made evaluations on the basis of client interviews, reports of current behaviors and abilities by care providers, a review of clients' history of adjustment in community placements other than family care, the rate of recent rehospitalization, and the age of the clients. Based on these factors and the OMH descriptions of levels of care for different populations (See Appendix B), it was determined that all clients were in need of long-term supervised care and treatment. Independent living, without supportive services, did not seem to be a viable living alternative for these family care residents. Although family care is the only available long-term alternative living arrangement, approximately 19 of the 47 persons in the sample could live in a more independent living situation. Partially supervised living arrangements such as cooperative apartments would be appropriate for these clients to further their growth and development. Considering the chronic nature of the disabilities of the sample population, this type of living arrangement must be accompanied with active and periodic supervision if it is to be a viable community placement option. Without the development of such alternatives, it is doubtful that family care will evolve towards a transitional living arrangement as envisioned

by OMH, but will remain a long-term community residential setting for the chronically mentally ill in the BPC catchment area.

3. BPC Services: The clinical services of Buffalo Psychiatric Center are provided by units organized on a geographical basis which provide psychiatric services to the residents of its catchment area. In addition, there are specialized units for geriatric and adolescent patients. The other distinct services provided by BPC include medical and ancillary services. Family care is considered a clinical service of BPC, and primary responsibility for supervising the homes and clients is assigned to a family care team in the geographic and special care units with family care residents. The family care program also is coordinated and monitored by a facility-wide Family Care Coordinator appointed by the Facility Director.

4. Day Programs: The day program component to family care should provide residents with opportunities to further develop their talents and learn new skills which will help them achieve their potential and enhance the quality of their daily lives.

The majority of clients in the sample, 35 out of 47, were participating in day activities. There was only one unit, Niagara, in which none of the clients in the sample

were attending a day program. After reviewing the records of other family care residents in this unit who were not part of the sample, it was found that they too were not engaged in day programs to the same extent as clients on other units. The major difficulty cited by staff was inadequate transportation services in that rural area. However, other BPC units responsible for similar areas had overcome this barrier.

Recommendation

FAMILY CARE HAS BEEN THE ONLY COMMUNITY-BASED SYSTEM OF CARE FOR MENTALLY ILL PERSONS IN NEED OF LONG-TERM CARE AND TREATMENT IN THE BPC CATCHMENT AREA. THE LACK OF OTHER ALTERNATIVE RESIDENTIAL PROGRAMS NOT ONLY EFFECTIVELY IMPEDES THE PLACEMENT OF RESIDENTS IN LESS RESTRICTIVE LIVING ENVIRONMENTS, BUT ALSO RESULTS IN PLACING PATIENTS ON THE BASIS OF AVAILABLE BEDS RATHER THAN ON THEIR INDIVIDUAL NEEDS. OMH AND BPC SHOULD ASSIGN PRIORITY TO THE DEVELOPMENT OF ALTERNATIVE RESIDENTIAL SETTINGS IN ORDER TO EXPAND THE RANGE OF COMMUNITY PLACEMENT OPTIONS.

CHAPTER I

BPC TREATMENT FUNCTIONS

Buffalo Psychiatric Center plays an integral role in the quality of treatment for residents in family care homes. The staff of the facility are responsible for services such as treatment planning, psychiatric evaluations, home visits, referral to day programs, and training of care providers. BPC staff also must ensure that each resident has an annual medical, dental and mental status examination.

1. Individual Service Plan: Prior to the placement of a patient in a family care home, a written plan is to be developed by BPC staff.<sup>2</sup> This plan, referred to as an Individualized Service Plan (ISP), requires the staff to identify the needs of each client and the services to be provided, as may be appropriate, in such areas as housing, medical care, psychiatric care, alcoholism treatment, finance, vocational/training services, education, self-care and transportation. As part of this planning effort, each patient also is to receive a medical examination, including a dental evaluation, which is used to assess the client's health care needs in the Individual Service Plan.<sup>3</sup> An evaluation of the ability of the client to self-administer medication also is to be contained in this medical report.

In reviewing the medical records, the required documentation on preplacement medical and dental examinations was most often not included in the patient's records. The physicians' recommendations regarding placement in a family care home as well as the medical factor affecting any placement were not available. Even though the physician is required to make recommendations as to the client's ability to self-administer medications, there was no item on the medical review form related to this evaluation.

Based on the review of treatment plans for the sample, a typical ISP could be described as follows. There is no provision for educational and vocational/training programs. The single nearest day treatment service provider is named in the social needs section regardless of the applicability of its activities to the client's needs. Although the next of kin is listed under "family and other support," discussions with care providers and clients indicate that no real efforts are made to contact family members or persons who frequently visited the client. Under "Self Care" there is no comprehensive assessment of client needs and strengths. BPC is listed as the only provider of mental health, mental retardation and alcoholism services, with no mention of other community services or even the identification of specific units at BPC responsible for providing care.

Although the purpose of the ISP is to encourage comprehensive service planning at BPC, it is clearly just another form to fill out. As such, it actually reflects the inadequate service planning which it was designed to correct.

Commenting on placement in family care homes, several BPC employees noted that very little is done to match a client with an appropriate family care provider. All too often this process consists only of finding an available bed and referring the client to that home. However, as noted by a supervisor, the placement process also can become one in which clients are placed according to the needs of care providers. In such cases staff, who have developed a protective relationship with the care provider, will place "good patients" (those with no behavioral problems and who require little supervision) in the homes of these providers.

The poor placement of clients was apparent to Commission staff on their numerous visits to family care homes. Some of the most regressed clients had been placed in homes which had what amounted to be a separate apartment, while higher functioning clients, who might have benefited from such independence, were living together with the care provider's family and were not given opportunities to engage in daily living activities such as housekeeping, necessary for independent living.

The failure in treatment planning was found in several of the cases reviewed by Commission staff. In one case,

Mr. W. was being considered for placement in a family care home. The client already had been placed unsuccessfully in two other homes and complained that he would rather stay at Buffalo Psychiatric Center than go back into another family care home. Nonetheless, the staff recommended that he be placed "into another family care home as soon as possible." The records did not indicate any effort by BPC staff to ascertain the reasons for the previous failures and to identify the type of home in which he could possibly succeed.

Another example can be seen in the case of Mr. G. This 59-year old man had successfully participated in the Psychiatric Center's hospital industries program in the 1960's and was described in a ward progress note as a person who "likes to keep busy running errands and doing chores around the ward." Contrary to his experiences at BPC, the ISP prepared for Mr. G. prior to placement indicated that vocational planning was not appropriate. In an interview, Mr. G. stated that he was a gardener by trade and enjoyed doing outdoor work in his current family care home. This satisfactory experience for the client developed by accident, and was not planned for by BPC staff in the ISP process.

The case of Mr. J. further demonstrates a disregard for a client's skills and experiences. Although he had been a cook on the railroads, his ISP did not indicate that this

skill could be further developed either in the family care home or in a vocational training program. There was no indication that staff even considered the ability of the client to apply for competitive employment.

However, there were some cases which showed placement was indeed based on the clients' needs. In one example, a Polish client was moved from one home to another home where the care provider not only spoke Polish but also prepared Polish meals. In another case, a Jewish woman had been placed in a Jewish home so that the client could observe her religious traditions.

2. Day Programming: Day programs are a critical component of a family care resident's treatment program. The Office of Mental Health requires the staff of its facilities to work with family care providers in developing "arrangements with local communities to provide residents in Family Care with programs and services."<sup>5</sup> This collaboration also is specified by OMH in the procedures for preparing the Individual Service Plan which stipulate that community providers of services are to participate in the design and implementation of the treatment plan.<sup>6</sup>

As previously noted, most of the clients in the sample (35 of 47) were in day programs. The effectiveness of these

services in improving the capabilities of clients and the overall quality of their lives was limited due to two major problems.

The first critical problem involving day programs was the lack of coordination and communication between the staffs of BPC and the community agencies. Community-based day program staff seldom were involved or included in the treatment planning even though the agency was to assume responsibility for providing rehabilitative services to the patient. BPC staff seldom provided the day care staff with an assessment of a client's needs. As a result, there was no mention of progress or problems of clients in day programs in the BPC records, again indicating little or no communication between staffs.

The quality of treatment and its evaluation is affected adversely by this fragmentation. In one case it was found that a client with epilepsy, who had been seizure free, had a seizure while attending the day program. The client reported that she had run out of anticonvulsant medication. The day treatment staff discussed the case with the care provider but apparently never informed BPC staff. The implications of this communication failure are most disturbing. Since there is no report of the seizure in the client's BPC chart, it is doubtful that the BPC psychiatrist treating this client ever knew that she had a seizure. In

addition to being unaware of the seizure and its cause, BPC staff could not counsel the care provider about keeping a supply of the client's medicines, or make spot-checks during home visits to see that the supply of medicines was adequate.

Second, the referrals made by BPC staff do not seem to be based on the needs of the clients. Out of the 35 persons in day activity programs, 33 persons were in recreationally oriented programs, and only two were in work or educational programs. Based on the home visit and client interviews, it would appear that at least 34 of the 47 clients in the sample could benefit from some kind of vocational rehabilitation services.

Related to the referral problem is the lack of extensive client involvement in these programs. The majority of the clients were not going to program five days a week, with some only attending two times per month. Although this low use was related to the lack of transportation and the frequency with which programs were open, there appears to be a wide variation in the quality and appropriateness of the day services. Although some programs did seem to provide appropriate care and treatment, most of these service providers seemed to offer little, if any, individualized services designed to enhance the abilities of family care residents.

3. Family Involvement: The potential support provided by family members and friends often is overlooked and not incorporated into treatment planning. The importance of the family is affirmed in OMH policy which requires that "every effort shall be made to obtain the approval of a resident's next of kin or guardian before a resident is placed in a Family Care Home."<sup>7</sup> If there is an objection to the placement which cannot be resolved by staff or the Chief of Service, the Facility Director is required to review the matter and determine if the placement is in "the best interest of the resident."<sup>8</sup>

Based on BPC records and care provider and client interviews, 17 families out of the sample had regular contact with the family care resident, while one resident had minimal family contact. The active involvement of several families highlighted the lack of recognition of the value of family interaction by BPC staff. Although the staff had made required contacts with the next of kin prior to any movement of the patient from one setting to another, there was no evidence that staff kept the family informed of the person's progress or encouraged greater family involvement.

Disregard for the family and their desires by BPC staff appeared to be an accepted practice, and in several cases was even documented in client records. In one chart, a staff person noted that a client wanted to see his elderly mother who lived in the Buffalo area. However, this staff

person assumed no responsibility for helping the client to make plans for this much hoped for visit. In a similar case it was found that two brothers, who had been living in the same family care home, recently were separated from each other. In an interview with one of the brothers, he stated that he did not know how to see his brother since BPC staff, who arranged the separation, had not helped him make arrangements for visiting or just remaining in contact.

There is additional documentation that showed an almost callous response to the desires of family members. In one case, a sister objected to a placement and asked that a different home be found for her sister. Rather than resolving the objection, as is required by OMH policy, the sister was not given any other option except to take the client into her own home. This same indifference was demonstrated when a family objected to a placement which would be a great distance from them. Since the family did not have a car, the placement would have made visiting very difficult. In response to this objection, the staff person advised the family that "unless they have an alternative plan...we (BPC) feel this is in the patient's best interests."

In many cases inaccurate and incomplete information about a family was contained in the record even though complete and accurate information easily was obtainable from

a client or care provider. For instance, one chart indicated that the address of a client's parents was unobtainable. These same parents consistently visit their son every Sunday at the care provider's home.

4. Facility Staff Visits: The Office of Mental Health in its policy manual requires that:

"Each resident in Family Care shall be visited at least monthly by staff of the facility and more often if necessitated by the needs of the resident." 9

However, in reviewing the records of the different units, only two BPC units, Geriatrics and East Genesee III, were in compliance with this OMH visitation standard. In both cases, every record reviewed in the sample showed that a monthly visit had been made. The records reviewed from the Southern Tier, Niagara, and North Units indicated only half or fewer of the cases in which a monthly visit had been made. In the South Unit and East Genesee IV Unit the records showed monthly visits in four of seven and three of five cases, respectively. In the Niagara, Southern Tier and North Units there was one case each where visits had been documented three or less times within the year.

Since this assessment is based on record reviews, there may be some discrepancies between visits actually made and those recorded. This may occur either due to failing to

record a visit or documenting a visit which did not take place. In several cases, workers wrote statements to the effect that the "client continues to do well..." without reference to how this finding was made, i.e., a telephone conversation or a home visit. In one case it was stated that "many home visits have been made since the last note." Clearly, such vague entries show little evidence that visits have been made, or more importantly, that the client is receiving proper care and treatment. However, based on interviews with care providers and clients, it is apparent that visits seem to be made at least once every two months. In all cases, the care providers were able to identify their BPC workers, as could the majority of residents.

Although monthly staff visits are required by OMH, good treatment would seem to dictate that more frequent visits be made during stressful periods for clients, including initial placement in a home. Based on staff interviews and record reviews, practice varied among the different family care teams. In three units, East Genesee III and IV and Geriatrics, staff always visited the home more frequently in the first month of placement. On the other units, increased visits were made only some of the time.

A case in which no home visits had been made in the first two months, that dramatically illustrates the need for increased visits upon placement, involved a woman with a

history of failure in numerous other family care homes. The client, who was also mentally retarded, had failed in previous homes due to regressed behavior which included smearing feces on walls as well as wandering around naked. Soon after the client was placed in a new home, the family care provider was permitted to take her residents on a two-month trip to Florida, thus, removing the new resident from contact with BPC staff during this critical period. Shortly after returning from Florida, the client was readmitted to BPC, and the provider reported that during her stay in Florida the client had shown the same regressed behavior. Upon the patient's admission to BPC, the nurse on inpatient services noted that this woman was "dirty and incontinent of urine, had a large hematoma (swelling filled with blood) on her left eye, bruises on her right knee, and a small moveable mass on her right arm." The nurse also noted that the client had lost 28 pounds since the last admission to BPC.

The staff on East Genesee III were the only BPC employees who consistently responded to stressful situations and made frequent home visits during these times. Although frequent visits during these periods seem appropriate, it appears that BPC staff sometimes do not even respond to complaints of disturbed behavior. An example of this involved a care provider who made several calls in one month to BPC reporting the very disturbed behavior of a resident. As noted in the case record, the care provider stated that

this resident was screaming at everyone in the house and accusing them of being against her. Although such behavior was regularly reported, BPC staff did not visit the home the entire month in which these calls were made.

As noted in the OMH policy manual, the purpose of the required monthly staff visits is to "evaluate the effectiveness and appropriateness of the resident's placement and programs in meeting the treatment objectives described in the resident's Individual Service Plan."<sup>10</sup>

The importance of these monthly visits in improving the quality of life for residents was demonstrated in a case where the BPC staff successfully encouraged a client, who had been a professional seamstress before her hospitalization, to take up sewing. Notes in the record indicated that her sense of self-worth was enhanced by this activity, and as a result she was able to make a good adjustment to living in family care for the first time.

However, most of the entries for these staff visits merely indicated that medication was delivered to the care provider or an injection given to a resident. The records provided little insight into how well or poorly a client was doing. The following are some typical examples of chart entries:

"As usual the client was neat and clean in appearance and offered no complaints."

"...continues to do well in the (T.) home. Offered no problems or complaints at this time."

"Client neat and clean. Watching TV. Came out to the kitchen, said 'Hello.' Stated she was good and the weather was nice and she went out into the yard to take a walk to get some fresh air. Came back in, said 'Hello, the fresh air was good.' and returned to watch TV. Offers no problem to care provider..."

In those few instances where staff noted problems with a client's treatment program, there generally was no change made. In one case a BPC worker wrote that Mr. G. was having difficulty managing his funds. Although this problem had been identified, no statement existed which indicated any effort was made to help the resident learn to manage his personal funds. In another case, Ms. Q.'s chart indicated that she was having difficulties getting along with the other client who lived in the family care home. There was no evidence that staff attempted to intervene in the situation or even encourage a family discussion to resolve the conflict. As such, the basic purpose of the staff visits was not being met.

One of the most flagrant examples of the failure of the monthly visits to identify problems and improve care involved a BPC employee who reported month after month that "the client was neat and clean and friendly on approach." This same entry was also found in the charts of four different

clients visited on three separate occasions. Commission staff found one of the four clients living in very poor conditions. In the one home, clients were living in a dark, dirty, barren apartment. Although a fire extinguisher was found in the home, it was still wrapped in a cellophane covered sealed box and hidden behind a refrigerator. The medications also appeared to be in a state of disarray, with old and new medicine bottles all containing medicine mixed together. The care provider, when asked which medicines were currently being used, pointed out a bottle filled with pills which, according to its label, was prescribed one-half year earlier. These conditions were not cited in the records of the home of the clients, and no efforts were being taken to correct these obvious problems. In this particular case, intervention by BPC staff could have resulted in improvements since the care provider was very cooperative and interested in making any needed changes.

The ability of BPC staff to assess the effectiveness of the treatment program is further limited by their home visit procedures.

Staff visits to family care homes are routinely announced visits. Rarely was a notation found in a chart indicating that a visit was unannounced. The only time such visits were made was when BPC staff were attempting to document unsatisfactory conditions in a home to justify removing the clients or to have the home decertified.

The second procedural deficiency was the general lack of staff contact with clients in the homes. In several cases, home visits repeatedly were made by BPC staff at times when clients were out of the home. In such cases, critical aspects of family life including client-care provider interaction could not be observed. Another major drawback is that BPC staff were not able to talk privately with the resident in the home. The Commission found that client interviews were instrumental in understanding the quality of home life and the effectiveness of the placement. Finally, some employees made their visits on the same day and at the same time on every occasion. In these circumstances, family care providers knew when to expect BPC staff and could prepare for the home visit.

The importance of such efforts was demonstrated clearly by one woman in the sample who related her past experiences in other family care homes. The woman related incidents of past abuse which were not reported since the workers "always talked to the caretaker" and never to her or the other residents.

In three homes, however, not a single client was capable of giving an accurate account of daily life. The disabilities of the clients were so severe that they had difficulty in describing their living conditions. In one home where conditions were very poor, two clients appeared to be delusional, one's speech was unintelligible, another client

was mute, and the fifth resident's memory was severely impaired. In another home with two residents, one client was mute and the second had a severely impaired memory. In the third family care home, the one resident spoke rarely and with great difficulty. Obviously, there are special risks which must be carefully considered when not even one resident is capable of describing life in the home.

The result of this failure to properly evaluate or assess the care and treatment in the family care home is a perpetual danger to ensuring quality of care for the residents. Not only are the residents denied the support and oversight which should be provided by BPC staff, but the family care providers are not given the assistance or guidance needed to improve the lives of the residents in their homes.

5. Evaluations: Family care clients generally receive two types of evaluations. First, for those receiving medication, OMB policy requires that a monthly evaluation be made of the individual's drug regimen.<sup>11</sup> The second assessment is a required annual examination which consists of a mental status, physical and dental examination.<sup>12</sup> In accordance with the Mental Hygiene Law, these latter examinations must be made for all patients receiving care and treatment by a State psychiatric center, which includes family care residents.

A. Monthly Medication Reviews: A vast majority of family care residents in the sample were taking medications that have serious effects and side effects. Frequent medication reviews allow the drug regimen to be monitored for its effectiveness and to be modified or maintained as may be appropriate. OMH policy stipulates that no more than a 30-day supply of medicine can be dispensed and that no prescriptions can be refilled. A review of the drug regimen is required to be made at least monthly. However, the policy does not require that physicians be responsible for the monthly review.

Based on reviews of the medical records, the practice at BPC shows minimal physician involvement in these periodic evaluations. In reviewing the medical records of the 47 residents in the sample, in only one case had the treating physician come close to meeting the monthly evaluation standard. This physician had seen a client 11 times during 1978. Approximately 43 percent of the residents received at least a quarterly evaluation by their treating physicians, while 57 percent were seen only twice a year or less. Twenty-two percent were not seen at all by a physician during 1978.

Frequency of Documentation - 1978	
Number of Evaluations	Number of Clients
0	10
1	11
2	6
3	8
5	7
6 or more times	5

Of the eight family care teams involved in the sample, four (Southern Tier, Niagara, North, and Adolescent) had documentation of physician reviews no more than three times in 1978. Two other units (South Unit VI and East Genesee IV), with the exception of one client on each unit, also had no more than three physician evaluations. The remaining two units, Geriatrics and East Genesee III, generally had documented evaluations by the treating physician on the average of once every other month.

This lack of direct involvement with family care residents also was reflected in interviews with physicians. Physicians seemed to regard family care residents as one of their lowest priorities, and they noted that it was impossible to know all the patients for whom they were clinically responsible. One psychiatrist employed part-time estimated

his caseload, including family care, to be between 500 and 700 clients. However, even when physicians had a limited number of patients, family care residents still did not receive appropriate attention. An example of this involved a psychiatrist who was responsible for only eight clients in three family care homes. When asked about the names of the clients, the psychiatrist responded: "I feel bad. I don't know." When asked how much time she spent on family care, the response was "Very little, I think I should give it up. I feel bad about it." The result of this neglect is that increased medical responsibility is placed upon nonphysicians. At the time of the Commission review, nurses on the North Unit were signing physicians' orders. However, documents indicated that social workers and therapy aides had been previously rewriting and signing the monthly orders for medicine. On the Niagara Unit, physician orders were signed by physicians, but they were written at irregular intervals with spans of three to eight months between orders. (See Appendix C for correspondence regarding medical care at BPC.)

B. Annual Evaluations: The Office of Mental Health prefers the required annual mental status, physician and dental examinations to be completed by community-based professionals.<sup>13</sup> The findings from these evaluations are to be sent to the appropriate family care worker for inclusion in the individual's chart to ensure necessary follow-up care.

In reviewing the charts for the sample population, the required physical and dental examinations were not properly documented. Although OMH requires these examinations to be recorded on DMH forms, Physical Exam, Form 34 Med and Dental Chart, Form 122 Med, the only indication that some form of medical examination had been made was the presence of lab tests results in the records. Based on these records, at least 36 clients in the sample had some form of medical check in 1978 or 1979, with one other client having an undated physical noted in the chart.

Of the remaining ten persons in the sample, eight clients had received some form of physical examination in 1977. The other two patients had no record of such an examination, with the record in one case containing a medical note stating that the client "has not had a physical for 2-3 years." However, it was not possible to determine how many of the remaining eleven clients, as well as the other 36 residents, were receiving medical care from community health care providers. Although family care providers indicated that they generally took their residents to a family physician or clinic for medical treatment, there was no documentation in the BPC records of these visits indicating a lack of communication regarding medical treatment.

Although it appears that some of these medical examinations were conducted in compliance with OMH policy stressing the use of community agencies, the mental status examinations, which were documented, were all made by BPC medical

staff. There were notations in the medical record regarding the mental status of family care residents, for the previous year, in 35 of the 47 cases examined. Of the remaining 12, the most recent notation for four clients was in 1977, one in 1976, and the remaining seven clients had no documented mental status examination in their record. The evaluation generally consisted of only brief modifications of previous psychiatric assessments rather than providing a comprehensive psychiatric overview as required by BPC. Since no State standards have been set for the mental status examination, BPC has established its own policy. The mental status should be:

"Sufficient in content to give a clear picture of client's emotional deficits and liabilities...summarizing diagnostic material, progress in care and prognosis, recommendations regarding ongoing treatment, prescription for psychotropic medications, client's known reactions to medication, etc., should be included."<sup>14</sup>

Family care residents are receiving some form of annual physical, dental and mental status examination. However, the failure of BPC staff to solicit the findings and recommendations of the community health care providers effectively impedes a comprehensive annual assessment of the client's physical and dental conditions from being made. The effect of the scant mental status examinations deprives clients from having a thorough evaluation of the need for

continued use of psychotropic drugs. Equally as important, BPC staff are unable to ensure that the residents obtain follow-up care and treatment indicated as necessary by the different examinations.

6. Training: In order for family care residents to receive a genuinely high quality of care and treatment, OMH requires that the facility-wide Family Care Coordinator develop appropriate training programs for care providers and facility staff involved in the program.<sup>15</sup>

The importance of and need for training was supported in numerous interviews with both BPC staff and family care providers. Although some providers had received training in the rudiments of first aid and had been given pamphlets on medications, many felt that they needed more training, especially in medical areas. Examples of training needs identified by care providers included suicide prevention and medication. Although such efforts probably are needed, BPC staff felt that more thorough training in the management of psychiatric symptoms should be a priority. As pointed out by one BPC physician, unless care providers receive this type of training it would be difficult to expect them to understand and to foster the movement of their residents to less restrictive living situations.

In discussing the need for provider training, one family care provider pointed out the inadequacy of BPC family care staff training. The provider said that BPC staff efforts had been less than satisfactory since they had been inadequately trained. The ability of family care staff to properly train care providers also was raised by a mental hygiene therapy aide on a family care team. This staff person noted that her lack of knowledge in the administrative areas of family care prevented her from being helpful to care providers. Rather than providing assistance, she noted that care providers often helped her, especially regarding new family care procedures which they often knew about before she did.

BPC staff not only need to be continually updated on new family care requirements or procedures, but also need training in clinical issues. Staff especially felt that their knowledge of medication effects and side effects was inadequate. Prior to the placement of a patient in a family care home, counseling is required to be provided to the care provider and the patient "as to the results expected from proper use and some of the most common side effects" of the prescribed medication.<sup>16</sup> In order for the family care staff to assist the care provider and monitor his or her effectiveness, it would seem essential for the staff to be fully aware of proper administration practices and the intended effects of the medications. BPC staff also stated that they needed training in the maintenance of treatment records.

BPC had no formal training program for new care providers and did not provide continuing education for the providers to improve their skills. Based on BPC staff interviews, it seems that the ongoing staff training programs at the Psychiatric Center are not reaching the family care staff or meeting their needs. (Subsequent to the Commission's field work, BPC has instituted a voluntary training program for new care providers and a continuing education service for all care providers.)

7. BPC Treatment Staff: As noted in the OMH Policies and Procedures Manual for family care, each facility is responsible for "developing adequate and appropriate allocations of staff and support monies for residents in Family Care."<sup>17</sup> The responsibility for this function is assigned to the Family Care Coordinator for the facility. The deficiencies found in the family care home and in the treatment of family care residents can be attributed to a great extent to the total lack of any BPC family care staffing plan. The inadequate involvement of professionals and the misuse of paraprofessionals are major staffing problems.

The direct care staff on the family care teams, excluding the family care team coordinators, consist almost entirely of mental hygiene therapy aides. Out of the 18 direct care staff on the teams, 15 persons are therapy

aides. The remaining three positions are held by a recreational therapist, a psychiatric social worker assistant, and a nurse who works three days per week. These three professionals all work on the East Genesee IV family care team.

The New York State Department of Civil Service's classification standards define the types of functions which therapy aides should assume:

"The specific tasks performed are directly concerned with caring for client's personal daily living needs and for implementing a portion of a treatment plan. These tasks are characterized by their being elementary and often repetitive..."<sup>18</sup>

"Although positions in this class may appropriately be assigned to programs within a community setting, this class does not include outpatient assignments which require independent counselling of clients and the performance of social service activities for a group of clients."<sup>19</sup>

The diverse clinical and administrative functions assigned to the mental hygiene therapy aides conflict with these State job standards.

Since therapy aides are being required to perform tasks beyond reasonable expectations, supervision of the direct care staff is extremely important. Based on interviews with staff and family care team coordinators, supervision is, in general, inadequate. Only three teams, Geriatrics and East

Genesee III and IV, had a structured system of supervision. On the other teams, the family care coordinators depended upon the direct care staff to bring their problems to them. These coordinators seemed to have an implicit trust in the capabilities of the staff to carry out their assignments, and as such did not periodically review the quality of their performance.

As previously noted, the medical care provided to family care clients is generally inadequate and poorly coordinated. The medical care or supervision at BPC was for the most part provided by physicians. There were nine physicians responsible for family care, six of whom worked part-time. Of the six part-time physicians, five worked one day or less per week on family care. These physicians were supplemented by two consulting nurses, both of whom were community mental health nurses. One of the nurses worked full-time and the other worked one day a week on family care. (See Appendix D for the distribution of medical staff.)

Only two teams had nurses in medical-related job positions, East Genesee III and the North Unit. However, these two teams had established organizational structures which impeded the coordination of the physicians and nurses on family care team staff. The Community Mental Health Nurse on the East Genesee III team dealt directly with the team's family care coordinator, while the consulting physician

provided assistance to the direct care staff. There was no established relationship between the physician and nurse. In contrast, the Community Mental Health Nurse on the North Unit had a staff relationship to the three part-time consulting physicians. Again, in this case, the consulting physicians rather than the nurse still dealt directly with the staff on the family care team. The potential contributions of the nurses to improving medical care were limited by these arrangements.

Although there were only two nurses involved in medical-related services, there were another seven nurses working on the family care teams. However, six of these seven nurses were serving in a full-time administrative capacity, with the other nurse working three days a week on the East Genesee IV family care team. Out of the six full-time nurses, five were family care coordinators. The other nurse was a family care placement specialist for the South V Unit, the only team with such a position.

Just as the organizational structures of the North and East Genesee III teams impeded the effective utilization of the nursing staff, the use of nurses as administrators likewise detracted from their ability to provide and supervise medical care. Given the major problems in the coordination of health care providers and the lack of full-time medical supervision of family care residents, more appropriate use of these staff should be instituted.

Recommendations

1. MAJOR IMPROVEMENTS IN TREATMENT PLANNING NEED TO BE MADE IN ORDER TO ENSURE THAT PERSONS PLACED IN FAMILY CARE ARE PLACED IN THE MOST APPROPRIATE SETTING AND WILL RECEIVE THE NECESSARY REHABILITATIVE SERVICES BASED ON THEIR NEEDS. THE FOLLOWING ARE SPECIFIC CHANGES WHICH SHOULD BE INSTITUTED.

A. The Individual Service Plan (ISP) process should be modified. The ISP should serve as a blueprint documenting the individual needs of patients and identifying the service providers responsible for meeting these needs.

1. BPC should coordinate service planning to include inpatient staff, family care staff, community agencies, potential family care providers, the patient, and his or her family or guardian, if possible, in the development of the ISP;

(Commissioner Prevost responds: This Recommendation is supported by the Office of Mental Health and has been implemented at Buffalo Psychiatric Center.)

2. OMH should establish standards for client visits to day programs prior to placement in order to assess the adequacy and appropriateness of the service. Such preplacement visits are currently required for family care homes; and

(Commissioner Prevost responds: The Office agrees with the need for preplacement visits to day programs prior to placement in family care, for those patients anticipating long-term family care tenure. However, for those who will be in family care briefly and are not hospital habituated, this recommendation is contra-indicated. This procedure has been established at BPC for appropriate persons and will be documented in the Individual Service Plan.)

3. OMH should require that preplacement vocational assessments be made, when appropriate, prior to the development of the ISP.

(Commissioner Prevost responds: With the introduction of the Problem Oriented Medical Record (POMR) at BPC, the need for preplacement vocational and education assessments will be mandated.)

B. BPC should comply with OMH standards regarding the performance of preplacement medical examinations.

(Commissioner Prevost responds: OMH agrees with this recommendation and will require that this be done and documented with a copy of the results of the examination in the Individual Service Plan. A comprehensive physical examination will be required for all clients being placed and/or discharged unless such an examination has been performed within the past six months.)

C. BPC should assess the characteristics of its family care homes and the abilities of its family care providers in order to better match patients with providers based on client needs.

(Commissioner Prevost responds: BPC staff routinely assess the characteristics of its family care homes and the abilities of its providers prior to placement and during placement in the home in order to the extent possible to match client with providers based on client needs. To further improve the matching of clients to family care homes (and providers), the following measures have been introduced.

(1) Cross-Catchment Referrals

(2) Centralized Recruitment of Homes

It should be noted that the closeness of the match between the client and the family care home within which the client is placed is dependent on the availability of homes at the time of placement. It is not OMH policy to delay significantly the placement of an individual within the family care program because of the unavailability of the "optimum" home. Thus, there must exist a balance between the available homes (and their characteristics) and the needs of the client.)

D. BPC should comply with OMH standards regarding the involvement of families in treatment planning. BPC should require family care staff to regularly contact families to foster greater family involvement in the care and treatment of residents.

(Commissioner Prevost responds: This is now occurring as outlined in our response 1A. above. Family contacts and further involvement will be thoroughly documented in the Conference notes, in the "progress notes," and in the Treatment Plan.)

E. Staff efforts should be thoroughly documented to assist in continuity of care in case of staff turnover or reassignment.

(Commissioner Prevost responds: ...it is agreed that record keeping has been deficient at BPC with corrective action to be taken as indicated in Response 2E.)

2. MONITORING THE EFFECTIVENESS OF THE HOME PLACEMENT AND TREATMENT PLAN SHOULD BE IMPROVED AS FOLLOWS:

A. BPC staff should comply with OMH standards regarding monthly visits.

(Commissioner Prevost responds: In April 1979, the Regional Office directed that BPC conform to the OMH requirement regarding monthly visits. This has since been monitored by the BPC Family Care Coordinator in weekly staff meetings and through record reviews. The Regional Office will conduct another review of records in October.)

B. OMH should require that monthly visits be made to the family care homes and specify that such visits should be made when the residents will be home. Such standards should also include a minimum number of unannounced home visits, which should be made at different times of the day.

(Commissioner Prevost responds: This is currently required. The Office will require that one third of the visits be unannounced.)

C. OMH should require periodic visitations by family care staff to day programs and other services being provided to family care residents, in addition to the monthly home visits in order to elicit candid responses to questions in the absence of the family care provider.

(Commissioner Prevost responds: OMH agrees with this recommendation unless this function is being accomplished by a case manager assigned from a CSS or other program, and will require on-site visits by family care staff to day programs or other community program services at least once every six months. These visits will be documented in the POMR progress note section. Also, "progress notes" will be requested every quarter as a minimum, from the Community Day Treatment Programs being attended by OMH clients. Further, Treatment Planning Conferences will be held once every six months with Community Day Program or other relevant staff invited to participate.)

D. OMH should require that visits be made more frequently than monthly during stressful periods such as initial placement in a family care home.

(Commissioner Prevost responds: OMH is in full agreement that, following initial placements, at least weekly home visits should be made for the first month for new placements. This latter practice should also apply to clients moved between homes and those returned to family care after being hospitalized.)

E. BPC staff should be required to more thoroughly document their visits to family care homes. Such documentation should at least include progress of the client, problems identified in the home, including physical and fire safety problems, and suggested improvements.

(Commissioner Prevost responds: As mentioned, BPC is planning to adopt the Problem Oriented Medical Record System which requires full documentation of problems, assessments, plans, and progress. A staff training program is underway and the need for full documentation is being stressed. This training is being supplemented with team training sessions and supervisory training sessions. Additionally, staff members from the Medical Records Office and the Centerwide Family Care Coordinator are visiting each team and engaging in on-site training with specific case materials. It is expected that the POMR System will be phased into the outpatient and Family Care Programs beginning in October.)

F. BPC should establish procedures for the regular and independent review of the clinical records of family care clients. Such a review should evaluate compliance with OMH and BPC standards in terms of substance and regularity, in such areas as the annual physical, dental and mental status evaluations, preplacement medical examinations, medical care and medication reviews, and the appropriateness and adequacy of the written treatment plan.

(Commissioner Prevost responds: This requirement will be met as part of the POMR audit process, which will be initiated in December, 1979.)

G. BPC should evaluate its placement practices and develop appropriate standards to encourage that at least one resident in each home is capable of describing life within the family care home. The grouping of disabled individuals, not capable of expressing themselves, within the same home should be avoided to the extent it is clinically appropriate.

(Commissioner Prevost responds: OMH agrees and a review has been initiated by the Centerwide Coordinator to identify homes where clients are not believed to be capable of describing the life within the home to staff. Where possible, given the limited number of placement opportunities, efforts will be made to correct this situation. In those instances where this is not possible, staff will provide more frequent contact and monitoring.)

3. THE QUALITY OF MEDICAL CARE MUST BE IMPROVED AND COORDINATED IN ORDER TO ENSURE BETTER HEALTH CARE OF FAMILY CARE RESIDENTS.

- A. OMH should modify its policy regarding monthly evaluations of each patient's drug regimen by specifically requiring periodic examination of residents by physicians. OMH policy currently only requires a review by facility staff.

(Commissioner Prevost responds: To provide a high level of medical supervision over the drug regimen of OMH clients, it will be required that monthly contact with the clients be accompanied by the completion of a behavioral and side-effect check list which will then be reviewed by the assigned physician. To assure that the necessary physician coverage is available to the family care provider and staff, the facility shall have a psychiatrist immediately available and/or on call at all times. Each client will be seen by a physician no less frequently than every six months for the purpose of medication review. These practices shall be implemented no later than November, 1979.)

- B. BPC should ensure that all orders for medication and any changes in dosage level are the responsibility of physicians. Signing of physician orders by non-physicians must be ended immediately.

(Commissioner Prevost responds: The problem of non physicians signing orders on one of the Units, as re-

ported 4 months ago, was corrected immediately. All Units are in full compliance with this policy.)

C. BPC should comply with OMH policy requiring pre-placement education of the family care provider and appropriate family care staff on the medications prescribed for the potential resident and its intended effects and possible side effects.

(Commissioner Prevost responds: With the significant amount of provider training (introduced since Spring, 1979) most providers have received detailed information pertaining to medications and their administration. Starting immediately, notes will be included in the provider's record pertaining to medication training and in particular, information pertaining to individual client medication instructions. Additionally, the family care staff member conveys this information to the provider either during the preplacement visit with the client or immediately at the time for the first home visit.)

D. BPC should comply with OMH standards regarding annual evaluations. BPC staff should be responsible for ensuring that each resident receives an appropriate physical, dental and mental status examination. Whenever such evaluations involve the use of community health care providers, BPC staff should be responsible for ensuring the receipt of such evaluations and the delivery of appropriate follow-up care.

(Commissioner Prevost responds: OMH has encouraged its facilities to utilize to the degree possible community providers for family care clients. Thus, more and more, especially within urban areas, family care clients are receiving physical and dental examinations and services within the community. However, in almost all instances, mental status examinations have been conducted by mental health professionals and physicians within the state facilities. Given the difficulty in obtaining physicians at medicaid rates, it is additionally difficult to obtain evaluations of care provided. However, this will be closely checked in POMR record reviews. Additionally, the Center-wide Coordinator has begun a monitoring of all family care records.)

E. BPC should adopt a problem-oriented recording method for physical health care documenting the short-term and chronic problems of family care residents. This method should identify the needs of a resident, health care providers responsible for treatment, and the progress and outcome of the treatment.

(Commissioner Prevost responds: As mentioned, BPC is adopting the POMR system for mental health and health care.)

F. Given the relatively limited time available from physicians, as well as their general lack of interest with family care residents, BPC should make better use of nurses

on the family care teams, including possible reassignment of nurses serving as family care coordinators. Nurses should be responsible for the health care of all family care residents in a unit. This responsibility should include identifying and monitoring the medical needs of clients and coordinating the delivery of health care services.

(Commissioner Prevost responds: The Office supports this recommendation. Nurses are employed on all BPC Family Care teams. They will be responsible for (1) reviewing the medical history and annual physical examination reports of all residents, (2) for being directly responsible for following up to insure that needed medical care is provided and, (3) for serving as a consultant to the team on medical matters. Additionally, the BPC Nursing Program Coordinator is examining the responsibilities of the psychiatric nurse within an outpatient family care unit.)

G. OMH should establish minimum standards for the required annual mental status examinations by the treating physician to include at least an assessment of the client's prognosis and ongoing need for medication.

(Commissioner Prevost responds: Minimum standards for the required annual mental status examinations will be contained within the new OMH regulations which will be promulgated for family care and alternative living.)

4. TRAINING PROGRAMS SHOULD BE DEVELOPED BY BPC FOR FAMILY CARE PROVIDERS AND FAMILY CARE STAFF. IN ORDER TO ENSURE THAT TRAINING EFFORTS IMPROVE THE QUALITY OF CARE FOR THE RESIDENTS, BPC SHOULD CAREFULLY ASSESS THE NEEDS OF BOTH PROVIDERS AND STAFF.

A. BPC should evaluate the effectiveness and utilization of the family care providers training program which was instituted after the completion of the Commission's field analyses.

(Commissioner Prevost responds: A family care training program was in development prior to the Quality of Care Commissions investigation. The following is occurring:

1. Before a family care home is certified, it is mandatory that a prospective careprovider attend a two full-day Orientation Program.

2. Continuing Education Program for careproviders is strongly recommended, but at this time is not mandatory for all careproviders. Sessions are held every other month for 3 hour periods.

3. Bi-monthly Unit Family Care Provider meetings are being held with Unit Family Care Staff.

The Office of Mental Health is establishing an "Educational Respite" mechanism which will allow a respite provider to stay in the home a certain number of hours while the regular caretaker receives training. The only help BPC

can provide now is possibly some Day Care assistance for clients during training meetings. End of session assessments by caretakers and staff have thus far been positive. In December, 1979, an assessment by Family Care Staff and the Department of Education and Training, and the Care-providers, will be made as to the effectiveness and utilization of the program.)

B. BPC should evaluate the effectiveness of its staff training program in meeting the needs of direct care staff in family care, and develop an appropriate program geared to their needs.

(Commissioner Prevost responds: Staff Training Programs, Formal Family Care Team Training programs were started July 10, 1979. These training sessions are mandatory for all family care staff; that is, Family Care Worker, Unit Coordinator, Centerwide Coordinator. The sessions are 2-1/2 hours each and are held bi-weekly. Initial emphasis is placed on treatment planning within the POMR system.

This Family Care Supervisory Training was started on September 1, 1979, and is mandatory for all Unit Coordinators and the Centerwide Coordinator. The sessions are 2-1/2 hours each and are held bi-weekly. Emphasis is placed on structure, role, supervision, and decision making.)

5. THE EXCESSIVE RELIANCE UPON THERAPY AIDES TO PERFORM DIVERSE CLINICAL AND ADMINISTRATIVE FUNCTIONS FOR WHICH THEY ARE NOT QUALIFIED OR TRAINED SHOULD BE CURTAILED AT BPC.

A. BPC should augment its family care teams with professional staff. The addition of such staff should foster a more active therapeutic involvement by BPC staff in the ongoing treatment of the resident. Increasing the clinical capabilities of the family care teams is essential if family care is to truly become a rehabilitative program.

(Commissioner Prevost responds: In the Centerwide Family Care Office, two recent changes have been made: (1) the new Centerwide Coordinator as of 7/2/79 is a Psychologist II, and (2) an Assistant (Psychiatric Social Worker I), has been added to this office as of 9/17/79 to handle more of the new centralized functions. The Assistant has a Master's Degree in Social Work. However, research has not demonstrated any correlation between the utilization of professional staff and outcome. In fact, highly trained professional staff are often not interested in working with the chronically disabled. On the other hand, competent supervision of well-trained paraprofessionals has been demonstrated to be very effective. OMH is in the process of studying staffing patterns both at BPC and Statewide. From this analysis, OMH will develop an organizational structure and staffing patterns for facility Family Care Programs. It

should also be noted that when speciality and professional services are required they will be provided by another program entity than family care, which is basically a housing program - not a rehabilitation service.)

B. BPC should set minimum standards for supervision by the unit family care coordinators to improve oversight of the performance of direct care staff. Such standards should include regular reviews of case records and periodically accompanying staff on home visits. The record review should specifically ensure that home visits are being made, and that problems in the home are being corrected.

(Commissioner Prevost responds: As previously noted, all BPC unit family care coordinators (7 staff members) are attending a supervisory training program (which ends 2/5/80) to strengthen their skills as first line supervisors and to define their specific job role and duties. Minimum standards for supervision are to be formalized no later than 11/15/79 by the Centerwide Family Care Coordinator in consultation with the Unit Coordinators. This will include regular reviews of case records and accompanying staff on home visits. Under BPC's POMR system, regular reviews of client records will be done at a minimum of six month intervals and these reviews will deal with the frequency and quality of home visits and the correction of problems which have been identified.)

Chapter II

LIFE IN THE FAMILY CARE HOME

The underlying concept of family care is to provide patients "with a home atmosphere which will meet physical and emotional needs in order to build strengths and abilities."<sup>20</sup> Although OMH has stressed the importance of the resident being viewed as a family member, in many family care homes clients had not been integrated into the fabric of family life.

1. Segregation of Clients: Although segregation of clients from the family can take very subtle forms, in over one-third of the homes the residents were physically segregated. In many of these cases clients actually had separate sleeping areas and literally had to live in designated areas within the home which were commonly inferior to other parts of the home.

In the city, care providers frequently owned two-family homes with clients living in one apartment and family members living in the other. Clients would eat, sleep and spend leisure time in these separate "apartments." Most often refrigerators and stoves in the client apartments were disconnected and clients carried their meals from the provider's kitchen back to the dining area in their own apartments. In some cases the client apartments were homelike and furnishings were of the same quality as those of the

family's apartment. In other cases, there was a marked difference between the apartments, with the provider's area being elaborately decorated while client areas were sparsely furnished and bleak. Although residents in these cases are not integrated into the home, the setting nonetheless best could be used for clients capable of functioning independently with minimal supervision. Unfortunately, clients were placed in such settings without considering their strengths and needs, thus depriving the more capable patients of an excellent opportunity for growth.

The other form of physical segregation from the family involved designated living areas. Family care homes both in the city and country were found to isolate their residents in this manner. One home in the country was decorated with paintings, china, knickknacks and lace on the furniture. However, five clients were found in a sparsely furnished room with the chairs arranged as if in a day room at a psychiatric hospital. Even though there was a strong odor of urine in the "client room," the windows remained closed to the beautiful weather outdoors. The sensation of entering this room was like that of leaving a home and walking into the old "back wards" of psychiatric hospitals. In another home in the country, the client's area was a small room approximately 8' x 10' in size. Four clients spent their time sitting in this room because they had been told that the living room was exclusively for the family.

In two homes in Buffalo, clients spent their leisure time in the basement. In one of these homes there was broken-down lawn furniture placed in the basement. There was no covering over the concrete floor and the room was poorly heated. (In this case, corrective action has been taken by BPC in response to an earlier Commission report. See Appendix E.) While visiting a third home, the family care residents returned from their day activity. The clients entered the home through the family's apartment, passed by the care provider without a word of greeting and went straight up to their apartment. Although the residents stated that there were no explicit rules about where clients could go in the home, the only time they went downstairs was at mealtime and on rare occasions when summoned by the provider. One client who had been in the home for several months said that he had yet to have a conversation with the provider.

There were other incidents which demonstrated a clear separation of the resident from the family. In two homes, clients were not allowed to use the telephone. This is in violation of OMH regulations which state that a "resident has the right to communicate by letter or telephone without censorship."<sup>21</sup> In another home clients were expected to be away from the home during working hours seven days a week. If they returned home before a designated time, they would not be let into the house. In one other home the clients

even had to buy their own toilet paper. Clients ate apart from the family in about 25 percent of the cases, and in two cases they had to purchase their own snacks.

There were, however, outstanding examples of the integration of residents into the family and its activities. On one unannounced evening visit, the client was in the family's living room surrounded by the provider's children merrily playing. The children related to this elderly client as if a grandparent. In another home, a client proudly showed a photograph of her provider's grandchildren. In other cases, clients regularly participated in such family affairs as baby showers and holiday meals. The most common shared event was attending religious services.

Being part of a family also entails work. The Office of Mental Health has noted that clients "should be encouraged to share responsibility for household tasks such as care of their own rooms, help with general cleaning, meal preparation..."<sup>22</sup> However, the residents are not to perform chores or work activities which are not performed by other family members. In the sample, clients were not being exploited but actually seemed to do too few chores rather than too many. In many homes the highest functioning clients were the only residents provided an opportunity to do housework of any consequence, while lower functioning clients did not perform household work. As such, the goal is more to get the job done than to provide opportunities for

learning new skills. The only semblance of improper work involved one home where a female client did the ironing for the family and clients, and the two male clients swept and mopped the floors of the provider's business twice a week. In this latter situation, the men were barred from the business at all other times.

2. Physical Conditions: The "housekeeping" standards governing family care homes are contained in Part 87 of the Rules and Regulations of the Department of Mental Hygiene.

"(The) dwelling unit and the grounds shall be clean and well maintained. The dwelling unit shall be kept free of hazardous physical conditions such as warped or damaged floors, loose or worn floor coverings, cracked plaster, loose tiles, broken windows, damaged or worn stair treads, loose handrails, burned-out bulbs, etc. The dwelling shall be maintained free of dampness, odors and vermin."<sup>23</sup>

The policies and procedures for OMH further state that it is the responsibility of the care provider to provide residents with a clean and cheerful environment, and a comfortable and adequate living and sleeping place.<sup>24</sup>

Based on these standards, six of the 25 homes visited (or nearly 25 percent) were found not to be in compliance. The problems found in four of the six homes include:

1. Roaches and dirty linen in a client's bedroom;
2. A dirty bathtub used by clients and a sink with little water pressure;
3. A grimy, sloppy client apartment with inadequate lighting; and
4. A littered, untidy living area.

In the other two homes there were intolerable odors which made it difficult to remain inside. The smell of human urine in a client sitting area was so intense that Commission staff gagged as they entered the room. In the other home, a dog and several cats defecated in the basement located right off the kitchen.

In order to ensure that family care residents are protected from dangerous situations, the Department of Mental Hygiene promulgated regulations establishing a "minimum level of safety." These requirements include standards for building or construction, smoke detectors, fire extinguishers and fire hazards, fire evacuation plans, door sizes, night lights and sleeping areas.<sup>25</sup>

Eighteen of twenty-five homes in the sample were free of dangerous situations. In the seven homes which were not in compliance, deficiencies were identified regarding fire extinguishers and smoke detectors. Problems related to fire extinguishers were found in six of the seven non-complying homes, while in five there were deficiencies related to smoke detectors.

Of the six homes with problems related to fire extinguishers, they were found in their original boxes never having been removed in two homes, while in a third home there was no fire extinguisher. The fire extinguisher was kept in the basement rather than in the kitchen in another home, while in the other two homes the fire extinguisher had not been inspected in one of them and had not been recharged in the other.

Although the unavailability of this fire equipment presents a potentially serious problem to the residents, even more disturbing was the general lack of knowledge among the care providers on how to use a fire extinguisher. In most cases, it seemed that the care providers would not use their fire extinguisher, even if readily available.

All family care providers are required to practice an evacuation of their home in case of a fire. These drills are to be rehearsed in order to "reduce anxiety and panic during a dire situation," and should be held at least quarterly with all family members and residents participating.<sup>26</sup> Based on interviews with residents in the sample, only rarely could clients adequately describe how to evacuate the home in an emergency. Adding to this danger was the finding that, as a rule, practice fire drills were not conducted in the homes.

In order to provide warning for a fire, all family care homes must have smoke detectors installed. The regulations require that the detectors be placed near the clients' sleeping area(s) and toward the living quarters but not in the kitchen nor near any corners.<sup>27</sup> The following deficiencies were found in the five homes not in compliance with smoke detector requirements. In three homes there were no smoke detectors at all. However, in one home, the provider stated that the smoke detector was being repaired. In the other two homes, a smoke detector was not located in the sleeping area, while it was missing in the living area in the other.

3. Medication Storage and Dispension: The medications commonly used by clients in family care homes are quite powerful and dangerous if misused. In order to prevent any person from taking more medication than prescribed or from obtaining drugs not prescribed, the Office of Mental Health has prescribed storage standards.

Storage and dispension of medicines is to be based on the client's ability to self-administer. Prior to placement in family care, a physician is required to examine the patient and determine if a client is capable of self-administration, requires supervision, or is not capable of self-administration. For those clients capable of self-administration, their medications may be stored "at the bedside table, chest of drawers, or closet."<sup>28</sup> However, if this

presents a danger to others in the home or is not in the best interests of the client, the medicine is to be kept in a locked storage area. The family care provider is required to monitor the habits of a client who self-administers, and to report to the facility if the client requires frequent prompting.

Those persons who are determined either to be able to self-administer when reminded and closely supervised or not to be able to self-administer, must have their medicine stored in a "locked storage area accessible only to the family care provider and designees approved by the facility staff."<sup>29</sup> The care provider is required to carefully supervise the dispensing of medication to persons capable of self-administering when reminded. In these cases, the care provider must take the client to the storage area, and after checking the container, hand it over to the client. The individual must be told the proper amount to take. Persons who are not capable of self-administration must have a registered nurse or a licensed practical nurse administer the medicine. (The arrangement for this must be stated in the Individual Service Plan.)

OMH also requires that the client and care provider be informed of the medication regimen.

"Prior to the individual leaving the facility and entering a family care home, the prescribing physician, or treatment team nurse, or the pharmacist, shall thoroughly explain and discuss with the individual and the family care provider the dosage regimen, the time of administration with respect to meals and other drugs, the dosage form and route of administration."<sup>30</sup>

In the survey, only six providers were in compliance with the storage standards. The majority of the providers stored medications in easily accessible kitchen cabinets, bedrooms, or medicine cabinets in the bathroom. In some of the homes visited, serious deficiencies were noted regarding storage and dispensing practices.

In one home, four varieties of medications were mixed and stored in a single bowl and kept on an open kitchen counter "for convenience." This bowl contained some 20-30 pills for the five clients in the home, and medicine which had been delivered five days previously was being kept in paper bags in an unlocked stereo cabinet. Regarding the administration of medication in this home, the care provider stated that one client "gets one of these white pills in the morning and two blue ones at night" while another resident "gets two of these red ones..." Also, a medication (Gerix Elixir) prescribed for one client was given to everyone since it was only a "vitamin." (Following up on on a Commission report on this home, BPC has removed all clients and has asked the care provider to surrender her certificate. See Appendices C and F.)

In another home visited in late January, 1979, Commission staff found indications that medications prescribed for clients were not being administered properly. In examining the medication containers, 49 chlorpromazine tablets were found remaining in one container dated September 27, 1978. Had the instructions for administration been followed, the medication in this container should have run out at the end of last October. After interviewing the provider, the possibility exists that either the client was not receiving the medication properly, or that the medication is being transferred from one bottle to another (See Appendices C and G).

In regard to dispensing practices, providers generally distribute the medications hand to hand, or use paper or plastic cups, and at mealtime will place the pill(s) by the client's table setting. Most clients were unaware of the medication and dosage prescribed for them. Likewise, the care providers lacked knowledge of the purpose of the medications, expected effects and possible side effects.

4. Medication Records: OMH policy requires that for family care residents not capable of self-administration, the family care provider must maintain a medication record in the individual's file indicating medications, dosages, and ways of administration.<sup>31</sup> The care providers are required to maintain this medication record (Form 604 DMH) and

make it available to appropriate facility staff. However, the care providers also must keep records of each administration of all medicines which show the name of the drug, dosage, time and date of administration, and the signature of the person supervising the administration.<sup>32</sup>

Although only one resident had been evaluated as capable of self-administering, more than half of the providers sampled had no knowledge of the specific DMH form or had incomplete records. There was no evidence that the record had been reviewed by facility staff. Even for those care providers fully aware of the medication record procedures, it was difficult for these providers to be in compliance since the DMH form provided to care providers is not designed to record daily or routine administration of drugs. (See Appendix H for a copy of this form.)

5. Incident Reporting: Fundamental to the oversight process is protecting and ensuring the physical health and safety of family care residents. As noted in the OMH family care staff manual, family care providers must notify the facility of any significant events in the lives of residents, i.e., unexplained absence, injury or serious illness, and BPC staff is to take appropriate action.<sup>33</sup> However, cases were identified which documented deficiencies with this process, especially in the area of incident reporting.

Inadequate action was taken relating to the absence of residents from two homes in the sample. In one case, a client's absence was properly reported to the local police department; the provider, however, did not promptly inform BPC. Although this incident had taken place over two years ago, no incident report had yet been filed in the client's record. In a similar case, no incident report had been filled out by BPC staff, even though the staff were aware of the client's absence from the home. The only documentation of the incident in the patient's record was an "Escaped Patient's Description" form filled out by a BPC family care employee.

The failure to file incident reports was most seriously noted in a case involving the return of a resident to BPC from family care. The resident, readmitted to BPC for behavioral problems, was found to have physical injuries upon examination. The client had bruises on the right knee and a small movable mass on the right upper arm. The resident also had an injury to her left eye, resulting in a swelling. The nurse, who made the entry, called the provider who stated that the injuries were sustained when the client fell out of bed a couple of days ago. This incident and the resulting injuries had not been reported. Although BPC staff suspected patient abuse, no investigation was made nor was an incident report filed by staff. (See Appendix I for correspondence related to this case.)

6. Meals and Snacks: Family care providers are responsible for providing their residents with "three well-balanced, nourishing meals and appropriate snacks each day" following dietary recommendations made by facility staff or physicians in the community.<sup>34</sup>

In most cases, the meals prepared by the providers seemed adequate. In only a few homes the main meal consisted of nothing more than a bowl of soup or chili with bread and a beverage, or a sandwich and a beverage. In many cases clients do not get second helpings, but most felt that their portion was sufficient. Almost every home complies with OMH standards regarding the number of meals, except for one home where the provider does not serve lunch on the weekends. The most common complaint was that snacks are not regularly provided.

7. Family Care Financing: In the course of performing this investigative review, twenty-five providers were interviewed. The question of the adequacy of the payment made to the providers, an issue which has been brought to the Legislature on several occasions, was never raised by any provider. (See Appendix J for a discussion of the financing of Family Care.)

Recommendations

1. GIVEN THE PATTERN OF SEGREGATION AND DEPENDENCE IN MOST FAMILY CARE HOMES, OMH SHOULD EXAMINE THE VIABILITY OF THE FAMILY CARE CONCEPT OF INTEGRATING MENTALLY ILL PERSONS INTO A FAMILY AND THE FEASIBILITY OF THE PROGRAM TO TRANSITION RESIDENTS TO LESS RESTRICTIVE LIVING SITUATIONS.

(Commissioner Prevost responds: Whereas some family care placements are viewed as transitional and time limited with the objective of moving residents to less restrictive and more independent living arrangements, other family care placements will be extended or long term. To further explain, it is planned that a continuum of family care homes be developed in consonance with that discussed within the OMH Balanced Service System concept, namely temporary, transitional, and indefinite.

To ensure that the level of care and length of stay is appropriate to meet an individual's needs, a type of Utilization Review process must be established and the Office is committed to this effort. In view of the large portion of the BPC family care population who are in the 70 and above category, it is expected that a significant percentage of these individuals would be most appropriate for the third category of family care homes, that is, indefinite.

Although the physical manifestations of segregation are most easily discernible, more importance is given to the areas of social and emotional isolation (segregation). A suitable and supportive living environment can often be provided, particularly where there are multiple placements, without the pretence of becoming "one of the family." We plan to adjust our guidelines to be more realistic and explicit on this issue.)

2. BPC FAMILY CARE STAFF SHOULD ACTIVELY ASSIST FAMILY CARE PROVIDERS IN DEVELOPING A MORE REHABILITATIVE ENVIRONMENT FOR LOW FUNCTIONING CLIENTS IN THE HOME. ENCOURAGING THESE CLIENTS TO PERFORM HOUSEHOLD CHORES RATHER THAN RELYING UPON HIGHER FUNCTIONING CLIENTS FOR ALL SUCH WORK WOULD BE AN IMPORTANT FIRST STEP.

(Commissioner Prevost responds: The BPC staff has been assisting family providers in creating a more active environment for the "low functioning" client. This assistance has taken the form of (1) training programs, and (2) on-site periodic visits for the purpose of consulting with and reviewing the activities of daily living (ADL) tasks being performed by clients.

In addition, the majority of the family care clients are provided day treatment services within a range of community-based Day Care Programs. The rehabilitation services are being delivered under the supervision of knowledgeable

staff found within the Day Care Centers. The OMH does not view the family care home/provider as the primary source for providing rehabilitation services. These services should be provided outside of the family care home.)

3. BPC STAFF SHOULD MORE THOROUGHLY ASSESS THE COMPLIANCE OF FAMILY CARE HOMES WITH OMH STANDARDS AND INFORM THE CARE PROVIDERS OF ALL DEFICIENCIES REQUIRING CORRECTION.

A. BPC staff should immediately evaluate compliance by all family care providers regarding the storage and dispensing of drugs with OMH standards. Corrective action should be swiftly taken.

(Commissioner Prevost responds:

Medication Storage: A complete on-site survey of medication storage practices was conducted during the latter part of April, 1979, in response to a memorandum sent by the BPC Centerwide Family Coordinator. In all instances where medications were not maintained in a locked cabinet, the staff informed providers of this requirement and subsequent visits (monthly) were made to inspect this storage practice. There is now virtually complete compliance with this storage specification. In addition to the family care worker reviewing the storage of medications, a further monitoring is being performed by the Unit Family Care Coordinator (first stage monitor). As part of its overall responsibility, the Regional Office is performing family care home visits and assessing the medication storage practice.

Dispensing Medication: Formal Training for care-providers was provided during the second Continuing Education Program session, on June 21, 1979, relative to the subject, "Medications and Clients". Another session on this topic will be held after the first of the year. The orientation sessions for prospective providers also covers medication administration. The bi-monthly Unit meetings with the careproviders have had entire sessions devoted to medications administration.)

B. BPC staff should more accurately assess the quality of the home environment and inform providers of deficiencies in physical and sanitary conditions.

(Commissioner Prevost responds: The responsibility for assessing the quality of the home environment and establishing compliance with OMH Fire Safety Standards has been shifted completely to the BPC Safety Officers, within the past two months. In order to expedite the correction of existing deficiencies, the Safety Officer provides a brief outline report to the provider immediately after the inspection. This initial briefing is followed up by a more extensive report (Form 236 Adm.).)

C. BPC staff should ensure that all care providers are in compliance with OMH fire safety standards and that prompt actions be taken to correct any existing deficiencies.

(See previous response.)

4. OMH SHOULD DEVELOP AN APPROPRIATE MEDICATION RECORD FORM WHICH IS DESIGNED TO RECORD THE DAILY ADMINISTRATION OF DRUGS WHICH WOULD ALLOW FOR THE "SIGNING OFF" EACH TIME A DOSAGE IS ADMINISTERED.

(Commissioner Prevost responds: The charting of individual medication administrations provides a record of medication administration compliance which cannot be achieved in any other manner. Therefore, for all family care clients who are not adjudged by physicians to be competent for self-administration of medication, the care provider will be introduced to and will utilize OMH-Form 223 for the recording of medication administration on a daily basis. Buffalo Psychiatric Center plans to develop the necessary instruction procedures, communicate this requirement to both family care staff and providers, and institute this form of medication record keeping no later than the month of October. Further, OMH will send a memorandum to all facilities requiring them to comply with these medication charting requirements for family care clients. This action will be taken during October, 1979.)

5. BPC SHOULD TAKE STEPS TO IMPROVE THE COMMUNICATION BETWEEN FAMILY CARE PROVIDERS AND BPC FAMILY CARE STAFF AND DAY PROGRAMS, ESPECIALLY REGARDING THE REPORTING OF SIGNIFICANT CHANGES IN A RESIDENT'S LIFE. BPC FAMILY CARE STAFF SHOULD BE ASSIGNED

RESPONSIBILITY FOR THE FILING OF ALL INCIDENT REPORTS AS MAY BE APPROPRIATE BASED ON COMMUNICATIONS BETWEEN THE PROVIDER AND STAFF. ALL FAMILY CARE PROVIDERS AND DAY PROGRAM STAFF SHOULD BE INFORMED OF THE IMPORTANCE OF REPORTING ANY POSSIBLE INCIDENTS TO THE APPROPRIATE BPC FAMILY CARE TEAM.

(Commissioner Prevost responds:

Careproviders

On July 23, 1979, a letter was sent to all BPC careproviders, regarding their reporting of significant changes in a client's life. Also enclosed with the letter was Part 10.6.5 of the Family Care Manual on the topic of "Notification to Facility Staff of Events in the Lives of Residents" and Form OMH 147 "Incident Report". This same information has been discussed in previous facility-wide careproviders' meetings and is scheduled again for the next meeting to be held in a month.

Staff

All of the Unit Family Care Coordinators received copies of the letter to review with their teams, and it has been discussed in the bi-weekly Unit Family Care Coordinators' meeting by the Centerwide Family Care Coordinator.)

(Commissioner's response continued:

Day Programs

To ensure that Day Programs serving BPC family care clients are aware of "Reporting any possible incidents to the appropriate Family Care team", the Centerwide Family Care Coordinator will forward a letter, in coordination with the unit teams, to some 40 programs serving our clients in the community. (Target date: Mid-October, 1979).

BPC family care staff are responsible for the filing of all incident reports, that are appropriate, based on communication between the provider and staff.)

CHAPTER III

ADMINISTRATION OF FAMILY CARE

Family care, established as an alternative to the institution as a living arrangement for mentally disabled persons, can be traced back to 1933 in New York State when it was established at Newark State School. The Newark family care program remained the only such program at any State facility until its expansion was authorized by Chapter 27 of the Laws of 1935 (State Purposes Budget).

The family care program has historically been administered by the State psychiatric centers. (See Appendix 15 which discusses the current scope of the family care program.) However, in 1976 the Central Office of the Department of Mental Hygiene was assigned overall responsibility for this program by statute (Chapter 805 of the Laws of 1975). The second major event affecting the administration of family care was an internal reorganization of DMH designed to decentralize Central Office responsibilities by assigning the regional offices administrative and regulatory functions. Although these two developments have affected the manner in which family care is administered, the responsibilities of the State facility directors over the program were not significantly affected. The division of labor among these three management levels was summarized in the 1979 OMH evaluation report of family care and community residences.

"In general, the facilities are responsible for the day-to-day operation of the program, the regional offices for monitoring and supervising the facilities, and central office for monitoring the regions and establishing policy."<sup>35</sup>

#### Central Office

Chapter 805 of the Laws of 1975 significantly expanded the role of Central Office in the administration of family care. The law, along with specifying functions for Central Office, required the Commissioner of the Department of Mental Hygiene to develop a plan for the creation of a central office of community residences and family care homes. It was clear that the intent of the proposal was "to centralize responsibility for the administration and coordination of community-based services for patients released or discharged to the community, including family care homes."<sup>36</sup> Numerous functions or responsibilities were assigned to the Commissioner of DMH in order to centralize administrative control over this program. The Commissioner was authorized to:

1. Develop standards governing the operations of a family care home;
2. Establish criteria for determining the appropriateness of referring patients to family care homes and the public need for such homes;
3. Establishing procedures for the issuance of operating certificates to family care providers;
4. Prepare a care provider's manual regarding the operation of family care homes; and

5. Develop a voucher system (now an advance payment system) to reimburse care providers for clients' expenses related to clothing, personal needs, and recreational and cultural activities.

The Legislature, in passing the State Purposes Budget for 1979-80 (Chapter 50 of the Laws of 1979), further centralized responsibility by establishing the program as a "major purposes item." This is an effort "to enhance accountability of expenditure of funds" for family care since this change will place administrative controls over the use of the appropriation and restrict any transfer of monies into or out of the program to five percent.<sup>37</sup> Any such transfers also would be subject to the approval of the Division of the Budget.

In accordance with the provisions of Chapter 805, the Central Office undertook two major efforts, the development of a family care manual and the promulgation of rules and regulations governing family care operations.

In August 1976, a provider's manual was published containing information on topics such as:

- The history and status of family care;
- Certification and evaluation;
- Accepting an individual in the home;
- Activity programs;
- Health care and nutrition;
- Transportation;

- Civil rights of residents;
- Record keeping; and
- Funding, taxation and legal concerns.

This process led to the development of a staff manual which identified, by subject matter, the policies of the Department and persons responsible for specific procedures to implement the policy. This manual, completed in December 1977, was based to a great extent on the newly adopted rules and regulations regarding family care. The regulations were officially adopted on August 24, 1977. The final regulations, Part 87, were included in the staff manual, and both documents were distributed not only to staff but were given to care providers as well.

Subsequent to the development of the Part 87 regulations and the manuals, the Department, and now OMH, has established or proposed policies or procedures in the following areas:

- Vouchering system for care provider reimbursement;
- Respite and emergency respite services;
- Personal care allowances for residents;
- Firearms in family care homes; and
- Travel expenses of care providers.

However, although authorized by Chapter 805, OMH has not established placement standards for family care homes or defined criteria for use in determining public need for new

family care homes.<sup>38</sup> Also, the policies and procedures of OMH relating to annual inspections of family care homes do not comply with the statutory requirements as enacted by the Legislature. Section 31.07 of the Mental Hygiene Law specifically requires that each provider with an operating certificate, which includes family care, be inspected twice a year. One of the two visits must be announced. Although two visits are to be made by facility staff, OMH does not require that one of these be unannounced.<sup>39</sup>

Chapter 805 also required the Department to submit an annual evaluation report of the family care and community residences program to the Governor and the Legislature.<sup>40</sup> The Department, and now both the Office of Mental Health and the Office of Mental Retardation and Developmental Disabilities, have submitted their annual reports to the Governor and Legislature. In its 1979 report, OMH reported the following administrative actions or undertakings:

- The formation of a new Bureau of Alternative Living and Special Programs;
- A complete review and reconceptualization of the family care program;
- Holding monthly meetings with representatives of Family Care Providers Association;
- An assessment of the "level of care" for all family care residents; and
- A proposal to develop a pilot project in Columbia County designed to increase Medicaid funding, and to provide trained care providers with additional reimbursement.<sup>41</sup>

Although the Legislature has required further administrative centralization, the OMH Family Care Manual and the 1979 OMH report on family care and community residences indicate major aspects of the management of family care still are delegated to the regional offices and the psychiatric centers. Central Office remains responsible for "allocating and monitoring all family care expenditures by facility."<sup>42</sup>

#### Regional Office

The regional offices serve as a liaison between local management and service providers, and Central Office. During the past year OMH has strengthened the role of regional offices with regard to the family care program. The regional offices are now responsible for the following major functions:

1. Certification - The regional offices are responsible for issuing operating certificates (as well as revoking them) based on the recommendations from the psychiatric center and the local governmental unit. (The role of the local governmental unit is limited to assessing the public need for any new family care homes.)
2. Periodic Assessment - Although the facilities maintain primary responsibility for visiting and inspecting family care homes, the regional offices are charged with monitoring the performance of the facilities by making site visits on a sample basis.

3. Fiscal Affairs - As previously mentioned, the Central Office is responsible for allocating and monitoring family care expenditures. However, the regional offices have assumed responsibility for monitoring the financial aspects of family care at the local level.<sup>43</sup>

However, the Western New York Regional Office is principally concerned with certifying family care homes and does not monitor the performance of BPC or analyze local expenditures. The principal reason for this, as cited by the then Acting Regional Director, is the lack of an adequate staff. Although each region should have a Family Care Coordinator to serve as liaison to Central Office, and to be fully informed about family care matters and policies,<sup>44</sup> responsibility for family care is divided among various program analysts who are responsible for monitoring all services within a given geographical boundary. This staffing pattern can provide an overview of the services in an area and may be used to encourage greater coordination among service providers. The scope of responsibilities is extensive and the result can be poor monitoring of programs with a low priority. This was evident when a program analyst in the Regional Office acknowledged that she had neither visited any family care homes nor used any system of checks while reviewing applications for family care operating certificates.

As part of its review of applications for operating certificates, the Western New York Regional Office should receive from each local governmental unit an assessment of

the public need for the family care home. The local governmental unit, which is the county mental hygiene agency, is charged by law for performing this function, along with the health systems agency and other area mental hygiene planning agencies.<sup>45</sup> As required in Section 31.23 of the Mental Hygiene Law, this review must consider the availability of other facilities which may serve as an alternative, the adequacy of financial resources and sources of future revenue, and the public need for the program, and that no action may be taken contrary to the advice of the health systems agency, unless it is afforded an opportunity to hold a public hearing.

In response to this legislation requiring a review of public need, Buffalo Psychiatric Center established an internal policy to prevent the approval of family care homes in communities saturated with such community-based programs. The BPC policy precluded the "opening of an urban home within a two block radius of an existing family care home or community residence, or, in rural settings, within a quarter of a mile."<sup>46</sup> Although BPC has developed a standard for its own review of family care applications, no such standard has been promulgated by the Commissioner of OMH by which to guide the counties in making this evaluation.

Based on interviews with the Erie County Department of Mental Hygiene, there appears to be a lack of coordination between the Regional Office and Erie County which further

limits the effectiveness of the certification process. Although Erie County is sent a standard form on all prospective family care homes, it is not able to properly review potential saturation. This is the result of two factors. First, the Regional Office has not supplied the local governmental unit with an updated list of all family care homes to be used in assessing the need for the proposed residence. Second, the need analysis is limited to post-1978 family care homes, thus avoiding a review of previously certified homes which may be located in saturated neighborhoods. The "grandfathered" homes are unaffected by this review process. Even though this process has added up to three or four weeks in the processing of family care applications, its usefulness is limited by these factors as well as by the Regional Office's perception that BPC would not recommend the approval of any home which would be inappropriate.

The result is that the Regional office is dependent upon the psychiatric center staff, and in essence, has delegated its management responsibilities to the facility. This reliance by the Regional Office upon the psychiatric centers was explained as follows:

"The staffs of the individual psychiatric centers are seen as adjuncts to the Regional Office in terms of their information-gathering, assessment and recommendation functions. In view of the magnitude of the Western New York Region, both in terms of the geographic size and the family care programs, it is both necessary and desirable to have many of the initial review and evaluation functions performed by the psychiatric center family care staffs."47

As noted by the then Acting Western New York Regional Director, the ability of the Regional Office to properly oversee the family care program, as required and expected by OMH, is impeded by the lack of adequate staff. Without such staff, it is likely that the Western New York Regional Office will continue to rely upon BPC to properly operate and manage the family care program.

#### Facility Administration

The psychiatric centers are responsible, in general, for the day-to-day operations of family care. In most facilities, a central Family Care Coordinator is assigned the administrative functions of family care including recruitment of care providers, training, and safety inspections, while the clinical management of the program involving such tasks as client placement, supervision of care providers, and medication management is provided by the geographic treatment teams.

In terms of carrying out the administrative aspects of family care, each Facility Director is required to appoint a Family Care Coordinator who is responsible for establishing facility-specific policies or procedures. Included among the policies are:

- Forming a Family Care Advisory Committee;
- Inspecting Family Care Homes for compliance with Department regulations, and recommending approval/disapproval to Regional Director for operating certificates;

- Developing adequate and appropriate allocation of staff and support monies for residents in Family Care.<sup>48</sup>

The Family Care Coordinator also is responsible for:

- Ensuring that the policies and procedures of the facility and Office are distributed to all family care providers;
- Maintaining a review of family care vacancies and the characteristics of family care providers and homes; and
- Making arrangements with other facilities for the sharing of family care homes.<sup>49</sup>

However, in reviewing the operations and policies at Buffalo Psychiatric Center, administrative responsibility is not assigned to the facility Family Care Coordinator, but to the Unit Chief of the respective geographical team. The Unit Chief, in turn, relies upon the family care coordinator to oversee the operations of the program. This assignment of administrative or regulatory responsibility to the clinical team was documented in a BPC memorandum regarding inspection of family care homes.

"It is the Unit Chief's responsibility to see that each family care home under the general supervision of his unit is inspected as required by law. The law also indicates that inspections may be made more frequently as deemed necessary."<sup>50</sup>