A Review of Private Residential Facilities for the Mentally Retarded:

Their Position in the Continuum of Care for Developmentally Disabled and Mentally Retarded Individuals

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

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The New York State Commission on Quality of Care for the Mentally Disabled was designated in 1980 as New York State's Protection and Advocacy System for the Developmentally Disabled, pursuant to Public Law 94-103 as amended.

A REVIEW OF PRIVATE RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED: THEIR POSITION IN THE CONTINUUM OF CARE FOR DEVELOPMENTALLY DISABLED AND MENTALLY RETARDED INDIVIDUALS

by

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

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PREFACE

In accordance with its statutory responsibility to ensure the quality of care of programs serving the State's mentally disabled citizens, the Commission conducted a review of ten private residential facilities for the mentally retarded in the fall and winter of 1981. This report contains the findings, conclusions and recommendations of this review.

The purpose of the Commission's study was to survey the range and caliber of services delivered by such facilities, to explore their problems and to review the position of these private facilities in the continuum of services for the mentally retarded and developmentally disabled of the State. Additionally, the report examines the development of the regulatory process since it was last observed in the Commission's report: Profit vs Care: A Review of the Greenwood Rehabilitation Center, Inc., (1981), and since the enactment of Chapter 720 of the Laws of 1979. In the approval message of July 13, 1979, Governor Hugh L. Carey requested the Director of the Budget and this Commission to monitor the implementation of this bill, which granted supplemental funding for the care of adults in any private school for the mentally retarded which is in substantial compliance with the terms of its operating certificate and all applicable rules and regulations governing its operation. This report, therefore, includes a review of the Office of Mental Retardation and Developmental Disabilities' interpretation of "substantial compliance" under Chapter 720.

The findings, conclusions and recommendations contained in the report represent the unanimous opinion of the Commission and have been shared with the Office of Mental Retardation and Developmental Disabilities, the Division of the Budget, the State Education Department and each of the private facilities reviewed. The responses of the Office of Mental Retardation and Developmental Disabilities, the State Education Department and the New York State Coalition of Private Residential Facilities for Mentally Retarded/ Developmentally Disabled Adults are appended to the report.

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ACKNOWLEDGMENTS

The Commission wishes to express its gratitude to the many people who assisted in the preparation of this report: the residents and staff of the private residential facilities included in the review; staff members of the Private Schools Unit of the Office of Mental Retardation and Developmental Disabilities; and representatives of the New York State Education Department and Coalition of Private Residential Facilities for Mentally Retarded and Developmentally Disabled Adults. Their hospitality, insights and comments enabled the Commission to better understand this care modality and to formulate recommendations to enhance the caliber of care afforded the residents of private residential facilities.

The Commission also wishes to acknowledge the efforts of its staff assigned to the project:

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Crystal Run Village (two campuses), South Fallsburg, New York, and Middletown, New York, (serving 277 adults and children);

Greenwood Rehabilitation Center, Inc., Ellenville, New York, (serving 173 adults);

Hebrew Academy for Special Children, Parksville, New York, (serving 36 adults);

Margaret Chapman, Hawthorne, New York, (serving 139 adults and children);

New Hope Rehabilitation Center, Loch Sheldrake, New York, (serving 148 adults);

Rhinebeck County School, Rhinebeck, New York, (serving 82 children in Fox Run--the Office of Mental Retardation and Developmental Disabilities certified portion of the school);

Upstate Home for Children, Oneonta, New York, (serving 38 children).

The visits focused on programmatic, environmental and certain administrative issues -- namely, routine medical management and incident review mechanisms -- and included interviews with staff and reviews of selected client and administrative records.

Commission staff also examined OMRDD certification records pertaining to the schools visited to determine the adequacy of the certification process -- that is, its impact on the quality of life within private residential facilities and its ability to ensure substantial compliance with regulations. (Substantial compliance for schools serving adults is a prerequisite for the receipt of "720" supplemental funding. Four schools in the survey were receiving such supplemental funds.)

Findings

(1) THE SCHOOLS INCLUDED IN THE SURVEY VARIED SIGNIFICANTLY IN THE POPULATIONS SERVED, THE CALIBER OF THE SERVICES OFFERED, THE QUALITY OF THEIR ENVIRONMENTS AND THE ADEQUACY OF THEIR MANAGEMENT OF MEDICALLY RELATED ACTIVITIES AND UNTOWARD INCIDENTS.

EXECUTIVE SUMMARY

Over the past four years in investigating deaths and allegations of abuse or mistreatment, the Commission has had the opportunity to review the operations of selected private residential facilities for the mentally retarded.* Also known as "private schools," today there are 18 private residential facilities certified by the Office of Mental Retardation and Developmental Disabilities (OMRDD) serving approximately 1300 developmentally disabled individuals.

On the basis of the findings of the Commission's "school-specific" reviews, as well as at the request of Governor Carey,** in the fall of 1981 the Commission undertook a systemic examination of the private school modality and its position within the State's continuum of care for developmentally disabled individuals.

In this endeavor, Commission staff conducted visits to 10 of the 18 private schools:

Arlene Training Center, Brooklyn, New York, (serving 16 adults and children);

Camphill Village USA, West Copake, New York, (serving 105 adults);

Cobb Memorial School, Altamont, New York, (serving 23 children);

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*See: An Investigation of Selected Incidents at the Otsego School, (January 1982); Profit vs Care: A Review of the Greenwood Rehabilitation Center, Inc., (March 1981); and, In the Matter of Cheryl J.: A Resident of the Greenwood Rehabilitation Center, (April 1980).

**Chapter 720 of the laws of 1979 created a funding mechanism by which private schools serving adults could receive supplemental funding if they were in substantial compliance with applicable regulations and met other criteria specified in the bill. In signing the legislation, Governor Carey requested the Commission to monitor its implementation.

were found at Hebrew Academy, Arlene Training Center and Greenwood. Required yearly physicals at Hebrew Academy appeared cursory and lacking in data which would identify residents' health care needs. This problem, however, paled in comparison to medication practices at Arlene Training Center which were seriously, if not dangerously, deficient. Medications were stored in mislabeled bottles, dispensed without doctors' orders, and were poorly charted and accounted for. It also appeared that Greenwood had made limited attempts to train its staff in first aid and cardio-pulmonary resuscitation, which was recommended more than two years ago following the death of Cheryl J., a Greenwood resident.

Schools also appeared to have inconsistent approaches to managing untoward incidents (a topic addressed in the Commission's 1982 report on the Otsego School). While Margaret Chapman had an exemplary system for reporting, investigating and reviewing untoward incidents to prevent their recurrence, the systems developed by other schools lacked clear definition of what constituted an incident and the purpose and methodology for investigating and reviewing such to preclude recurrence.

(2) THE REVIEW ALSO INDICATED THAT THE REGULATORY FRAMEWORK GOVERNING THE PRIVATE SCHOOL MODALITY IS MULTIPLY LAYERED, WEAK, IDIOSYNCRATIC AND FAILS TO PROVIDE CONSISTENT APPROACHES TO CORRECTING PROBLEMS. THUS, IT FOSTERS THE VARIABLE CONDITIONS FOUND DURING THE SURVEY (pp. 43-47).

A. While a number of agencies share responsibility for funding or monitoring the schools (including the State Education Department, Department of Social Services and

A. Of the ten schools surveyed, three (Cobb Memorial, Rhinebeck and Upstate Home for Children) served only children. Four others (Camphill Village, Greenwood, Hebrew Academy and New Hope) served only adults. The remaining three (Arlene Training Center, Crystal Run and Margaret Chapman) served both children and adults. The clients themselves ranged in age from 6 to 60 and, while some were mildly retarded, others were severely retarded or suffered multiple physical or mental disabilities.

B. While the habilitative and educational services offered children generally appeared adequate (Report pp. 6-14), the quality of programs for adults was uneven (pp. 14-22). In contrast to a school such as Camphill Village, which offered its adult residents a range of well-planned, individualized and age-appropriate skill building activities, the programs of Arlene Training Center, Greenwood and Hebrew Academy were limited by a lack of challenging opportunities for higher functioning adults or inadequate treatment planning.

C. Environmentally, the schools ranged from exemplary (pp. 24-26) to abysmal (pp. 27-31). At Hebrew Academy, for instance, bathrooms were dirty and unsanitary, walls were in need of scraping and fresh paint, and furnishings were old, damaged or inadequate in number. Margaret Chapman's Sherman Hall, which housed approximately 90 children and adults, was similarly deficient. There, visitors were greeted by exposed pipes, peeling paint, damaged bathrooms and uncarpeted lounges.

D. Striking contrasts were also found among the schools in the adequacy of their management of medically related activities and untoward incidents (pp. 33-42). While most schools appeared to have adequate mechanisms to attend to the health care needs of their residents, problems

A. The dangerously deficient medication practices at the Arlene Training Center were cited by OMRDD in December 1980. Although the Center agreed to remedy the deficiency, such was not done until the Commission found the same deficiency nearly 12 months later. During that one year period, OMRDD took no action to ensure that the dangerous medication practices were corrected.

B. OMRDD certification records indicated that the abysmal environmental conditions at Hebrew Academy and Margaret Chapman's Sherman Hall have existed for years. Not only have the deficiencies gone uncorrected but, in the absence of indicators of substantial compliance, both facilities have been granted supplemental funding intended for facilities which are in substantial compliance with regulations.

Recommendations

In order to ensure a uniformly high caliber of care for private school residents, action is warranted on both a systemic and school-specific basis.

1. The Commission recommends that all agencies involved with the private schools join in an effort to formulate one set of regulations that govern all certification issues, and that the agencies conduct joint visits and issue joint reports to the maximum extent practicable. The ideal to be strived for is the attainment of a certification process that provides the facility and each of the oversight agencies a comprehensive and integrated view of the quality of life at the schools. Toward this end it is recommended that a task force, consisting of representatives from OMRDD, the State Education Department, Department of

OMRDD), there is no comprehensive set of regulations governing private schools. Consequently, oversight agencies, each operating on the basis of its own regulatory requirements, have a myopic view of the schools, and no single agency has an all-encompassing view of the quality of the private school modality as a whole. In fact, at times, the recommendations of one oversight agency may be overturned by another.

B. In the absence of clear and comprehensive regulations, schools are at times subjected to the varying interpretations of staff engaged in the oversight process. Conditions found to be deficient at one school may not be deemed so at another school, although similar if not identical conditions exist.

C. Often acting without the benefit of sound regulatory guidance, schools develop operating policies and procedures which are, in many cases, inadequate as was found in reviewing incident reporting and medication practices.

D. Compounding these problems is the fact that the schools rely on a three-person unit of the central office of OMRDD for technical assistance while all other providers of service for the developmentally disabled rely on regionally based OMRDD personnel for such assistance. This reliance tends to isolate schools from the resources available, and often necessary, at a local level to resolve problems such as finding alternative placements for clients, seeking community-based day programming services, etc.

(3) FINALLY, IDIOSYNCRATIC OVERSIGHT AND A LACK OF FOLLOW-UP, AS WELL AS AN ABSENCE OF INDICATORS OF SUBSTANTIAL COMPLIANCE, HAVE RESULTED IN IDENTIFIED DEFICIENCIES REMAINING UNCORRECTED FOR LONG PERIODS OF TIME AND THE GRANTING OF SUPPLEMENTAL FUNDS TO SERIOUSLY DEFICIENT SCHOOLS (pp. 47-50).

schools and the needs of their clients to the resources available through County Service Groups which monitor and provide assistance to all other mental retardation agencies in their catchment areas.

4. It is further recommended that a needs assessment of the 1,300 persons in private schools be undertaken. The present and future residential, vocational and educational requirements of this population, especially those residents who are aging and growing enfeebled, should be addressed and planning begun to meet the identified needs.

5. Finally, it is recommended that, for the purpose of determining "substantial compliance," OMRDD develop a system for assigning weight to critical compliance issues. When an oversight agency is faced with the challenge of enforcing a diverse set of regulations which range from requirements concerning maintenance of meeting minutes to requirements concerning substantial life safety and environmental issues, it is imperative that minimal criteria be established which all schools must meet in order to be considered in substantial compliance.

In an effort to correct those deficiencies specific to particular institutions, the Commission offers the following recommendations:

6. Hebrew Academy for Special Children.

The OMRDD report dated May 1980 certifying the facility until April 1982 cited numerous environmental violations (some originally cited as far back as 1973) including unsanitary bathrooms,

Social Services and Department of Health be created for the purpose of designing the consolidation of regulations and oversight activities. We recommend that this body welcome and encourage input from the private schools themselves and submit periodic reports of its activities and a final report of its recommendations within one year to this Commission, the Commissioners of the affected State agencies, and the directors of the schools.

2. This Commission has cited major environmental, programmatic and health-related deficiencies which, despite their identification by OMRDD, have been allowed to continue for years without correction. It is therefore recommended that OMRDD set reasonable time limits for the implementation of corrective actions and that certification granted to the facility during this correction period be conditional and revoked if corrections are not implemented on a timely basis.

3. To further advance the integration of the private schools into the mainstream of the mental hygiene delivery system, it is recommended that the dual functions of technical assistance and certification presently the responsibility of the Private Schools Unit within OMRDD be divided, with the Private Schools Unit retaining the certification function and the County Service Groups serving as technical advisors. This will enable the certification unit to vigorously monitor compliance issues and the implementation of plans of correction at the schools. At the same time, this will better align the technical assistance needs of the

8. Margaret Chapman.

(a) The environmental conditions in Sherman Hall have been investigated in the past by the OMRDD Schools Unit, the Southeastern County Service Group, Westchester Developmental Center, and this Commission. Although some changes have been made, substantial problems remain. The Commission recommends that Margaret Chapman be instructed to make non-structural changes in this building. Each resident should have a dresser in good repair and a chair. No child should be in a bed with peeling paint. Toys that are clean, safe, complete and unbroken should be readily available in the lounge used by the children. The lounges should have living room type furniture and rugs on the floor. Decorations and personalizing items should be provided. We further recommend that the County Service Group be charged with the responsibility for monitoring these improvements and that they report to this Commission quarterly on the progress made by Margaret Chapman.

(b) Secondly, the Commission recommends that OMRDD review the plans submitted by the school for the construction of a new dining area and the conversion of the present dining room to lounge space, and if the plan is acceptable, facilitate its movement from plan to reality by whatever means it has at its disposal.

(c) Finally, the Commission recommends that the County Service Group assess the Margaret Chapmen population and make substantial

need for furniture repair, painting and lack of sufficient chests and chairs. Since the facility is presently receiving 720 funding, this Commission recommends that the OMRDD ensure that these funds are used to correct environmental deficiencies and improve the quality of life at the facility. Additionally, a financial audit of the use of the clients' wages and personal allowances is also recommended.

7. Arlene Training Center.

In view of the fact that the seriously deficient medication practices noted during the Commission visit had been cited one year earlier and no corrections had been made, we recommend that the County Service Group give immediate technical assistance to this institution to bring it into compliance with standard medical practice. We request that the County Service Group advise this Commission of the details of the program they establish for the school and of the monitoring procedure they will use to insure its implementation.

The area of programming for the adult residents at the Arlene Training Center remains a serious problem. In an effort to find meaningful vocational training and employment opportunities for this population, the Commission recommends a program review of the Arlene Training Center which considers, in addition to an evaluation of the existing programming, client assessment and placement. The vocational program that is presently in operation should undergo a critical evaluation and the possibility of using community resources should be fully explored.

a skills assessment of their populations for the two-fold purpose of identifying those residents ready to move to a less restrictive environment and to identify those skills lacking in residents who will soon be ready to move.

* * *

In their responses to a draft copy of this report (included in Appendix A), the Office of Mental Retardation and Developmental Disabilities, State Education Department, and New York State Coalition of Private Residential Facilities for Mentally Retarded/Developmentally Disabled Adults largely concurred with the Commission's observations and recommendations. Specifically, the Commissioner of the Office of Mental Retardation and Developmental Disabilities stated that the:

> ... OMRDD concurs that new regulatory base is warranted. Development is going forward and OMRDD will keep the Commission apprised of progress. It is anticipated that the new regulations will incorporate a system for assigning "weights" to specific requirements, to address the issue surrounding the definition of "substantial compliance" and to further insure the consistent application of standards for which OMRDD is striving. With regard to the environmental, programmatic and health-related deficiencies cited in the draft report, OMRDD has been actively working to remedy existing problems through several means. These include the issuance of time-limited certificates with addenda indicating required actions; the monitoring of plans of corrective action through site visits and correspondence; and the rendering of technical assistance, using the resources at the Office's disposal.
>
> ... OMRDD concurs with the recommendation that a needs assessment for the residents of the schools be undertaken. It is the perception of the OMRDD that the schools themselves are best situated to complete this task, with monitoring and appropriate assistance. The Commission will be apprised of progress in this regard.

efforts to find appropriate alternate living situations for those clients capable of more independent functioning. As residents are moved out of Margaret Chapman, the census in Sherman Hall should be correspondingly reduced and no new admissions accepted.

9. Greenwood Rehabilitation Center.

The Commission recommends that the County Service Group provide Greenwood with technical assistance aimed at providing comprehensive programming to meet the habilitative, social and vocational needs of the residents. In addition, the Commission recommends that the Private Schools Unit at OMRDD monitor closely the programming offered at Greenwood to be sure that it is in compliance with all of the rules and regulations (NYCRR Part 81.6) that govern programs in schools for the mentally retarded.

10. Finally, the selection of appropriate candidates for residency in schools such as Greenwood, Hebrew Academy for Special Children and the Arlene Training Center, where opportunities for community interaction are severely limited, must be undertaken cautiously. The fact that mildly and moderately retarded residents with significant capabilities (e.g., those who can participate in clerical skills classes) are placed in these restrictive environments raises questions regarding the selectivity of the admissions procedures and the rigor with which the institutions seek community contacts and opportunities for work and recreation beyond their walls. This Commission recommends that these institutions undertake

... OMRDD concurs with the recommendations regarding the organizational locus and mandate for provision of technical assistance and performance of certification functions. As stated earlier, the central Private Schools Unit was established to provide a centralized focus to this class of providers. Its functions were and continue to be of time-limited duration. The unit has been successful in performing the first phase of priority initiatives assigned to it, is ready to undertake a second phase, and has begun the transition of some functions to other units. All of these activities will ultimately lead to certification, inspection and monitoring responsibility resting with the Division of Quality Assurance and with direct technical assistance resting with the DDSOs and County Service Groups.

INTRODUCTION

Re-enacted time and again in countless homes across this State is the tragic scene of a family forced to admit it can no longer care for a mentally retarded child. Twenty or thirty years ago, families unable to provide care at home for mentally disabled relatives had to reconcile themselves, in many cases most painfully, to placement in a State institution. Some families could not or would not accept this. Such families, joined in part by humanitarian and religious groups and by private entrepreneurs who also saw the need for a more humane and personalized residential setting for the mentally retarded, created an option more acceptable to themselves -- the private residential facility for the mentally retarded. Presently, these facilities, numbering 18, serve some 1300 developmentally disabled individuals.

The original aim of this study was to provide a body of site visit reports to serve as baseline information. With the availability of Chapter 720 funding, the initiation of fee-for-service billing and conversions to not-for-profit status and ICF/DDs,[1] many private residential facilities, also referred to as "private schools," will be undergoing significant changes in the near future -- changes which will undoubtedly impact on the caliber of services for the schools' residents.

Additionally, it was the intent of this Commission to examine the development of the regulatory process since it was last observed in Profit vs. Care: A Review of the Greenwood Rehabilitation Center, Inc. (1981) and since the

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[1] An Intermediate Care Facility for the Developmentally Disabled (ICF/DD) is designed to provide intensive care through a combination of services, structured programs and 24-hour residential arrangements.

enactment of Chapter 720 of the Laws of 1979. In his approval message dated July 13, 1979, Governor Carey requested the Division of the Budget and this Commission to monitor the implementation of this bill, which granted supplemental funding for the care of adults in any private school for the mentally retarded which is in substantial compliance with the terms of its operating certificate and all applicable rules and regulations governing its operation. Pursuant to this mandate, the Commission has included in this report a review of the Office of Mental Retardation and Developmental Disabilities' (OMRDD) interpretation of "substantial compliance" for purposes of Chapter 720.

This report then seeks to explore the private schools -- the range and caliber of their services, their problems and their position in the continuum of services for the mentally retarded in an age of increasing treatment alternatives.

Nature and Scope of Commission Review

In the fall and winter of 1981 Commission staff undertook a review of private residential facilities for the mentally retarded in New York State. During each announced site visit, Commission staff toured the residential and on-site program areas. A record review of treatment plans and individualized education plans (IEP) yielded information on assessment methods, long and short-term goal identification and program implementation. Additionally, each selected case record was reviewed to determine whether the delivery of mandated health care services was accomplished in an appropriate and timely fashion.

Generally at the conclusion of each visit, the directors of the facilities were invited to share with the Commission staff any concerns or issues. They were encouraged to offer their own perceptions of their program, its strengths and weaknesses, their priorities, their plans for the future.

Commission staff visited ten schools, representing both large and small facilities, rural and urban ones, long-established and newer facilities, not-for-profit and proprietary schools, schools for children only, schools for adults and schools which serve both children and adults. This sample, which represents over 50 percent of the total number of private residential schools for the mentally retarded certified by OMRDD, is comprised of the following schools (approximate number of residents follows in parentheses):

Arlene Training Center, Brooklyn, NY (16 adults and children);

Camphill Village USA, West Copake, NY (105 adults);

Cobb Memorial School, Altamont, NY (23 children);

Crystal Run Village (2 campuses), South Fallsburg, NY and Middletown, NY (277 adults and children);

Greenwood Rehabilitation Center, Ellenville, NY (173 adults);

Hebrew Academy, Parkville, NY (36 adults);

Margaret Chapman, Hawthorne, NY (139 adults and children);

New Hope Rehabilitation Center, Loch Sheldrake, NY (148 adults);

Rhinebeck Country School, Rhinebeck, NY (82 children in OMRDD certified portion of school);

Upstate Home for Children, Oneonta, NY (38 children)

At the conclusion of the site visiting phase of the review, Commission staff undertook an examination of the certification reports for the selected schools prepared by OMRDD. It is the responsibility of this agency to inspect and certify residential schools for the mentally retarded. This review brought to light, in conjunction with conversations with the directors, the interplay between OMRDD and the New York State Education Department (SED), the Department of Social Services (DSS) and the Health Department (HD) which share with OMRDD oversight and/or funding responsibilities.

Organization of the Report

The subsequent chapters of this report detail the results of site visits and record reviews at the selected facilities in three major areas:

1. Programming - including educational programming for residents under 21, vocational and prevocational programming for adult residents, and training in activities of daily living (ADL);
2. Environment - including the internal environments of common and personal space and the environment of program areas; and
3. Administrative concerns - focusing on the incident reporting and review system and the delivery of mandated medical services.

The certification process and the relationship of the private schools to other service agents within the mental hygiene system are explored in Chapter IV. Finally, the concluding chapter enumerates the findings and recommendations that emanated from the review of the private residential schools.

Chapter I
PROGRAMMING

Any consideration of programming in the residential schools for the mentally retarded and developmentally disabled is best preceded by a description of the populations served. The ten schools visited serve some 1,000 residents between the ages of 7 and 55. The heterogeneity of this population is noteworthy. Some schools (Cobb, Upstate and Rhinebeck) serve only children; some serve both children and adults (Arlene Training Center, Crystal Run and Margaret Chapman) and the remainder serve only adults. Some schools serve only the mildly and moderately retarded (Hebrew Academy); some serve clients whose psychiatric disabilities are as debilitating as their mental retardation (Rhinebeck), and some serve residents with significant physical impairments (Upstate). Some schools provide programming for everyone within the school itself (Cobb, Upstate, Arlene Training Center, Camphill, Hebrew Academy and Greenwood), and some secure community-based programming for nearly all of their residents (New Hope).

Those schools that serve children are required to make available an education program which meets standards established by the NYS Department of Education. Cobb Memorial, Upstate, Arlene Training Center, Rhinebeck, Margaret Chapman and Crystal Run provide on-site educational programming for children. Schools serving adults offered a range of programming options from programs focused on prevocational and daily living skills to those which include on-site and community sheltered workshop experiences. While each of these programming options offers the possibility for excellence, striking contrasts in the quality of actual programming were evident in each sector -- adult and children's services.

Programs for Children

In reviewing the educational program for children and adolescents in the schools, Commission staff paid particular attention to assessment techniques, the adequacy of the individualized education programs (IEPs), the continuity displayed in the selection of behavioral objectives from year to year, the relationship of actual classroom activities to the prescribed plan and the mode and subsequent use of data collected. In addition, staff made note of general classroom environment and those observable indicators reflective of the relationship between teacher and child, e.g., the posture, tone of voice, attentiveness of each.

Upstate Home for Children. The Upstate Home for Children is a not-for-profit facility in Oneonta, New York which presently serves 38 moderately to profoundly retarded residents ranging in age from 7 to 21, many with significant physical disabilities in addition to mental retardation.

As Commission staff members toured each classroom, they noted the variety of activities available in attractively furnished activity centers. Quiet space was available with reduced visual and auditory stimuli, an arrangement particularly appropriate since it provided a "recovery area" for a number of children with seizure disorders. The concerned, consistent approach of the staff was evident throughout the facility.

During snack time in a classroom of younger children, each staff member employed the same strategies to keep the youngsters on task even to the point of using identical phrasing. This approach proved successful -- these highly distractable children were able to peel oranges, eat them, and look at storybooks until everyone was finished and the snack area cleaned up.

In reviewing the IEPs for two students, one known to Commission staff and the other randomly selected, Commission staff found them to be timely, complete and appropriately written in behavioral terms. Signficantly, skills learned in the summer session were identified for refinement and/or amplification in the fall individualized plans. The classroom activities of the two children chosen for review were reflective of the short-term behavioral objectives identified for each in his IEP.

Cobb Memorial School. Another program characterized by its excellence is that provided for young children at Cobb Memorial School in Altamont, New York, a not-for-profit private institution administered by the Sisters of the Presentation. All of the 23 residents and two day students are ambulatory and most function in the moderate retardation range.

Commission staff observed that each of the younger children, who comprise 25 percent of the school's population, receives individual one-to-one instruction in all subject areas except physical education. Communication is the core curriculum. All residents and staff use a total communication approach (verbal language accompanied by sign) to encourage communication between verbal and non-verbal youngsters. In addition to speech and language specialists, an art teacher, a physical education teacher and a developmental specialist work along with three classroom teachers.

Programming efforts for the older girls are focused on self-help skills defined in this instance as sewing, knitting and cooking. Commission staff watched a group of older girls working on a knitting project. A display of samples of finished products the young women had made in the past was, indeed, quite impressive. The teacher conducting the class pointed out that the young women especially enjoyed making gifts for their families.

This class of five residents to one instructor was the largest class Commission staff observed in the program. Even physical education classes contained only five students who seemed dwarfed in the large gym. The staff-to-student ratio in the classroom, in this instance, has effectively maximized the children's learning opportunities. Commission staff noted that all of the teachers in the classrooms were directly interacting with students and every child was occupied productively. An additional programming component worthy of mention is the consistent methodology employed in teaching daily living skills. Cobb staff members explained that when a child awakens in the morning, he is taught to dress himself using exactly the same techniques that his teachers will use when he changes for gym. A task analysis of other daily living skills, such as toothbrushing is used, again, to insure consistency.

Each of the two case records Commission staff reviewed at Cobb, one randomly selected and one of a resident known to Commission staff, was divided into seven parts, facilitating access to the substantial quantity of material amassed for long-time residents. Each record contained monthly progress notes written by the housemother, a quarterly progress review and the results of the annual treatment conference with contributions by the administrator, teachers, nurse, social worker and psychologist. Both records contained the results of bi-annual psychological testing and semi-annual psychiatric evaluations. The IEPs examined were carefully done. Goals were set twice a year (September-December, January-June) and each specific behavioral objective from last year was followed by a closure date and a note regarding the level of accomplishment. In reading the last three years' IEPs for one student, they

showed a definite progression in skills taught and competency level considered acceptable. Also reflected in the case records examined by Commission staff in addition to individualization of behavioral objectives, the school day schedules of various ages of residents differed markedly according to their needs. Motor, self-help and social skills occupied two hours and 45 minutes of classroom time per day for the younger children. This was significantly reduced for the older students, and reading, math, hygiene skills and crafts were added to the program.

Having indicated the substantial merits of this program, an area of consequential programmatic deficiency remains; namely, the lack of vocational training available to the women students who remain until they are 21. The Director was able to recount only a very few graduates of the program who have successfully secured competitive or sheltered employment. Thoughtful consideration must be directed toward the initiation of programs, beyond training in domestic skills, specifically designed to meet the future employment needs of these women.

Margaret Chapman School. The Margaret Chapman School in Hawthorne, New York, presently a proprietary school scheduled for conversion to not-for-profit status, serves 45 mentally retarded children and 94 adults. Although only students with a primary diagnosis of mental retardation, ranging from mild to severe, are admitted, an appreciable number of residents present behavior problems.

The children have been divided into five instruction groups based on developmental level and degree of socially appropriate behavior. One teacher and one teacher aide instruct each group of seven to ten children. The youngsters aged 16-20 are provided instruction in a room specially equipped to foster prevocational skills. The room,

divided in half by a partition, contains on one side a simulated work activity area where each student punches in on a time clock and works under simulated on-the-job conditions on a sorting task building up appropriate social and "on task" skills. The other section of the room is furnished as a bedroom and is used to teach youngsters those skills necessary for maintaining their personal environment. Title I funding makes this program possible and also funds a weekly community trip for these 19 students.

The youngest children, aged 11-13, are grouped together under the direction of a teacher and an aide. Additionally, however, this classroom is used as a "training ground" for adult residents at Margaret Chapman who show aptitude and interest in working with young children, preparing them for eventual employment as a teacher's aide. During the time the Commission staff visited the program, the aide-in-training was escorting a child to the bathroom to show him how to rinse his paintbrushes.

Documentation in each of the case records reviewed by Commission staff included minutes of a monthly meeting focused on each child and attended by his primary therapist (case coordinator), teachers, speech therapist and physical education instructor. Each child's progress is reviewed quarterly when all of the above staff meet with the addition of the cottage parents and health personnel.

Both of the two IEPs reviewed were written in compliance with mandates calling for annual and short-term goals written in behavioral terms. The IEPs from the previous year had the goal completion dates filled in and explanatory phrases were added where necessary. Psychological testing in accordance with the Education Law was completed every three years. Each of these evaluations reviewed contained a cautionary remark that standardized test scores were not to be used as the sole criterion when considering placements or program.

The aspect of programming which distinguishes Margaret Chapman is its use of community volunteers to enhance existing programming and the degree of utilization of community resources for recreational programming. School administrators explained that college students from Westchester College, the College of New Rochelle, and several other institutions, volunteering their time, provide recreational activities at their own colleges for the children every afternoon of the school week.

Saturday recreational activities, such as swimming at the "Y" and community trips are supplemented by volunteers, and high school students run a Boy Scout troop for residents. In addition, the school encourages volunteers from the community to help out on campus. The director showed Commission staff a gracious welcoming letter and a packet that provides basic information on developmental disabilities, standard procedures and issues of confidentiality, etc., that is sent to each volunteer. Each volunteer is assigned to a specific staff member to whom the volunteer can address questions and concerns.

No other school that Commission staff visited viewed itself as such an integral component of the community-at-large as does Margaret Chapman.

Rhinebeck Country School. Situated on over 200 acres of land, overlooking the Hudson River, Rhinebeck Country School, a proprietary facility, serves 163 youngsters in three separate programs -- Fox Run, Meadow Run and Spring Wood. Fox Run, the largest of the programs, serves 82 children between the ages of 9 and 21. All of these children are mentally handicapped (IQ scores between 45-70) and also manifest a significant degree of emotional disturbance. Fifty percent of these children are maintained on phenothiazines and twenty percent present symptoms of severe

neurological dysfunction. The Meadow Run program serves 41 students with lesser degrees of intellectual impairment (IQ range 70-95). Many of these children show severe learning disabilities and subtle seizure disorders. The third program, Spring Wood, focuses on the needs of 40 children of normal or superior intelligence who, because of their acting-out behavior, have been excluded from public school.

As pointed out by the Director, notable programming features at Rhinebeck include the multiplicity of evening activities available to residents, the requirement for parental involvement and the recognition of work as a restorative agent. Between 6:00 p.m. and 8:00 p.m. some twenty clubs meet on campus several times a week. At the beginning of each semester, each resident must choose five clubs to attend. Boy Scouts, Girl Scouts, pillow making, rug hooking and cooking are among the possibilities. Thus, each student is busy five evenings a week with an activity of his choice. As one tours the dormitory area, one can see many examples of the children's work in the common rooms and bedrooms. Medals, trophies and photos of proud children at work decorate the assembly room.

In Rhinebeck's endeavor to provide a total therapuetic environment, the administration advises the parents of students that their full cooperation is necessary and expected. The director noted that all children must return home for four two-week vacations each year. Treated as an equal partner in the treatment team, parents use the home visits as an opportunity to secure the specialized medical assessments and services which their children may need and which are not available in the Rhinebeck area due to its distance from a major metropolitan center. Behavior management techniques are discussed with the parents prior to the

child's vacation and the parents must keep careful notes in this regard and write a "vacation report" that is returned with the child. A number of these "vacation reports" were included in the case records reviewed by Commission staff. Staff at Rhinebeck reported that they discuss all discharge plans with the parents and impress upon them their responsibility to act as the child's primary advocate when he is returned to the community.

Each youngster, in addition to making his bed and tidying his own personal area, is assigned one chore for the upkeep of the common rooms. In addition, the adolescents help to maintain the impressive outdoor environment. Residents run the tractors and lawn mowers and volunteer the fact that they are paid for their labor as part of the vocational program. Others in this program perform food service duties -- setting the tables for meals, bussing the dirty dishes and cleaning the dining area after lunch. Students also tend a large vegetable garden and orchard. This resolve to provide meaningful work for maturing students demonstrates the institution's belief, as stated by the administration, in the inexorable link between work and self-esteem.

The student body is divided into instructional groups according to functional level. While the size of particular classes range from 6 to 11 children, the staffing ratio is either one to six or one to four. As would be anticipated, a multi-sensory approach is used with the most disabled students. This basic curriculum is supplemented by art, music, home economics, physical education and speech and language. A baseball field, soccer field, gym, swimming pool and basketball court are available. Staff feel strongly that large-muscle physical activities and access to the outdoors are essential components of a therapeutic

milieu. A resource room equipped for tutorial sessions in reading, language and math and for individual testing is provided for all children who come from New York State and Massachusetts (the two states that fund the program). Each of the six classrooms Commission staff visited had at least one teacher and one aide in attendance. All of the rooms and hallways were decorated by the children with their own work.

A review of two randomly selected IEPs found them complete and written in behavioral terms delineating annual goals and short-term instructional objectives. An annual case review is standard and input from the clinical, residential and educational components of the child's program is synthesized to create a total program that emphasizes consistency in methodology and expectations. Quarterly reviews are held to assess the need to modify goals or intervention strategies.

Programs for Adults

The number of adults (over age 21) who reside in private residential schools for the mentally retarded far outnumber their younger counterparts. For a substantial number of these residents, the private school has been home for many years. The provision for meaningful work, vocational training, the creative use of leisure time and access to personal funds are critical issues in the delivery of service to developmentally disabled adult residents. The Commission undertook a consideration of these and closely related issues for five schools representing both rural and urban settings that serve this population.

Camphill Village. Situated on 580 acres of farmland in West Copake, New York, Camphill is a community of 105 "villagers" (residents) and 100 "co-workers" (staff) founded on the principles of Rudolf Steiner, espousing total integration between residents and staff to maximize each person's potential for spiritual, interpersonal and vocational growth.

One of the villagers acted as tour guide for Commission staff members as they traversed the woods and pastures hoping to get a feel for life at the Village. Commission staff watched villagers and co-workers working side-by-side in the shops, fields and homes. Given the liberty to choose and "try out" work assignments allows villagers the opportunity to develop valuable skills. Some villagers were weaving, some binding books; others were woodworking, polishing copper for enameling, dipping candles, baking bread, feeding animals, cleaning and dusting; and still others were preparing food for the noontime meal.

At lunch each villager returned to his home to share the meal with his housemates. Under the careful and subtle direction of the houseparents, villagers were encouraged to share their morning's experiences around the table. After the meal, villagers helped to clear the table and put the kitchen in order before enjoying private time until work resumes at 2:00 p.m.

In discussing life at the Village, co-workers noted that recreational opportunities are plentiful. There is a pond for swimming and picnicing. Evenings bring dances, choral performances, and play productions. Many of these events, as well as religious services, take place in "Fountain Hall," a large multi-purpose meeting hall and library.

Camphill Village is in many respects unique among facilities for adults who are mentally retarded and developmentally disabled. Its philosophy secures for villagers a supportive community; its location and geography secure independence in movement; and its economic practices secure meaningful and varied work for villagers which directly contributes to the maintenance of the Village.

New Hope and Crystal Run. Located in the Catskills, both New Hope, a proprietary facility and Crystal Run, a not-for-profit organization, serve large numbers of adults (combined total of approximately 425). Many of the original residents of both of these facilities came from Letchworth Village and Wassaic Developmental Centers. Programming in the form of day treatment and sheltered workshops in the community is provided for 70 percent of the adult residents. The remaining adult residents work on prevocational and academic skills within the facility in anticipation of their transfer to community programs.

The considerable opportunities available to Crystal Run residents to develop recreational skills are noteworthy. Commission staff toured program areas set up for woodworking, ceramics, general arts and crafts, music, sewing and horticulture programs. Staff members informed Commission staff that these activities are available evenings and weekends. An opportunity to participate in student government and to contribute to the student newspaper likewise fill leisure hours constructively.

Both facilities complete annual treatment plans for each resident which include treatment goals and treatment methods. In both facilities goals were non-specific and, in many instances, not individualized in the two case records reviewed at each facility. At New Hope, Commission

staff, during the tour of the facility, selected two day programming students and compared the treatment objectives to the residents' actual activities. In both cases the residents' activities were those delineated in the treatment plan.

Hebrew Academy for Special Children. Hebrew Academy, a not-for-profit enterprise, occupies a converted three-story hotel which serves as the total work and residential space for 36 mildly and moderately retarded adults. Serving populations similar to those in New Hope and Crystal Run, Hebrew Academy offers an alternate programming option to the community sheltered workshop.

All residents work in a sheltered workshop located in the basement for five and one-half hours a day, five days a week. The workshop itself is one large room housing nine separate operations. There are two staff on the floor supervising residents who perform assembly tasks or quality assurance duties. Residents are paid semi-monthly. The residents' money is kept in the office and residents purchase many of their incidental supplies from a canteen located on the third floor of the facility. In cooperation with Sullivan Community College, three residents have been evaluated for training in clerical skills and the use of a pocket calculator. These students attend class one evening a week on the college campus.

In order to evaluate the process used to determine placement in the workshop, Commission staff reviewed the case records of one randomly selected male resident and female resident. Each record contained a psychological assessment performed tri-annually, a yearly habilitation plan and an annual progress report written in cooperation

with the executive director, program director, psychologist, nurse, special education teacher, workshop supervisor and houseparents. Problems surfaced when the goals in the habilitation plan were inspected for specificity and applicability. Both records contained such goals as "Marion will learn to get along better in the workshop." Because of its lack of parameters, progress toward the goal was extremely difficult, if not impossible, to measure. Consequently, while the semi-annual reassessments have in the past been timely, the new goals were, in too many instances, rewordings of the previous ones.

The Greenwood Rehabilitation Center. The Greenwood Rehabilitation Center, located in Ulster County at Briggs Highway in Ellenville, New York, serving 173 adults, offers much programming within the facility. Greenwood, however, is not equipped with a workshop. Rather, programming focuses on daily living and prevocational skills. This kind of programming, because of its all-encompassing nature, demands careful attention to defining behavioral objectives, methodology and sequencing. For this reason, and because the Commission in a previous review uncovered serious programmatic deficiencies which included the absence of multi-disciplinary treatment reviews to meet the social, vocational and rehabilitative needs of the residents, Commission staff undertook a careful review of the assessments and individual program plans for four residents. Serious deficiencies surfaced at the conclusion of this review.

Goals and objectives were often meaningless, reflecting little critical thought and evidencing a lack of understanding of pedagogical principles. Progress notes were perfunctory at best and would lead one to the observation

that direct care staff are being given responsibilties for program development far beyond their capabilities and are working with inadequate professional guidance.

One direct care evening staff member (a houseparent) and one direct care daytime staff member are jointly responsible for the completion of a comprehensive evaluation of strengths and weaknesses for the residents in their charge, using an adaptive scale which scores items according to the degree of independence the resident has achieved in performing the task. Likewise, these same two staff members are the authors of the individual program plan including semi-annual goals and short-term objectives for the residents in their care. It is the daytime direct care staff who conduct classes offering instruction appropriate to the goals and objectives.

Samples of semi-annual goals from two of the records Commission staff reviewed read as follows:

(a) Lucille will further develop appropriate behavioral characteristics.

(b) Lucille will further develop time concepts.

(c) Edward will increase social development with peers.

(d) Edward will increase daily living skills.

There is little individualization, and the goals are so all-encompassing as to be appropriate for a lifetime of learning.

A selection of short-term objectives, which are reportedly re-evaluated bi-monthly, read as follows:

(1) Lucille's requirement for frequent excessive reassurance will decrease by 50%.

(2) Lucille will correctly recite the days of the week 50% of the time.

(3) Lucille will tie a partial tie in her shoe lace 3/4 of the time.

(4) Edward will interact with peers 50% of the time.

(5) Edward will shave with an electric razor 75% of the time.

Examination of the treatment plans for these two individuals failed to show any method of implementation for any of the goals. Nowhere could Commission staff find any baseline information upon which to evaluate success or failure, any material that addressed how a particular objective was to be achieved, who was to be responsible for the instruction, how often instruction was to take place, or where or when it was to be offered. Similarly, to write that Edward will interact with peers 50 percent of the time may, at first glance, look like a quantifiable behavior. However, given the fact that there is no single staff member assigned to follow Edward around and count his social interactions, the goal, because of its lack of paramaters, becomes inapplicable.

Progress notes were equally problematic. Progress notes for Edward from September 1981 and November 1981 read as follows:

> 9/81 - Edward needs much assistance from staff. To continue goal. (No indication which of the four goals this refers to.)
>
> 11/81 - To continue goal. No improvement.

Notes on Lucille were equally as non-specific:

> 9/81 - Progress observed. ITP continues.
>
> 10/81 - Needs verbal assistance and sometimes physical (refers to bedmaking).
>
> 11/81 - Progress observed. ITP continues.

Concomitantly, there was no closure on last year's plans or any evidence of continuity in the selection of behavioral objectives from year to year. Administrative staff attributed this lack to the fact that the facility had switched to a new assessment instrument in the fall of 1981 and had based all of the present year's goals on the new assessments. In inspecting the Adaptive Scale (the assessment tool), Commission staff observed that Lucille was rated as able to write her name independently (a skill that was supposedly worked on last year), but one month after the rating was done, Lucille was not able to sign her service plan and only made an X.

Within the last year administrators of Greenwood have entered into contracts with the Sullivan County Association for Retarded Children and the United Cerebral Palsy Association of Sullivan County to provide day treatment and vocational rehabilitation and training in addition to clinical and therapeutic services such as speech therapy, physical and occupational therapy. These arrangements have facilitated the movement of Greenwood residents into the community for day programming. In May 1982 approximately 25-30 persons were leaving each day for off-campus programming.

Arlene Training Center. Although quite dissimilar in size and geographic area, serving 16 moderately retarded students in a residential section of Brooklyn, the Arlene Training Center and Greenwood Rehabilitation Center share similar programming modes. No longer able to attend a community-based sheltered workshop, Arlene's adult residents now receive in-house programming as do the children. Commission staff were able to observe units of programming for two discrete groups: the upper intermediate adults (ages 21+) and the upper intermediate adolescents (17-20).

Vocational training for the upper intermediate adults is housed in a converted garage several feet to the left of the residence. These residents (who had up until last year successfully functioned in a sheltered workshop) were gluing popsicle sticks together to make baskets. The school's principal reported that cleaning and baking are also taught in this area (a refrigerator and stove were available) and that once a week this group makes lunch for itself and a less able group. Commission staff also observed an academic lesson involving the adolescents. This lesson centered on the identification of body parts, specifically ears. These adolescents were identifying ears on a felt board character, a face puzzle and on the teacher. Each student responded correctly each time he was questioned.

The lack of aggressive programming noted above was clearly in evidence in the four randomly selected treatment plans that Commission staff reviewed. The treatment plan for a mildly retarded adult female resident showed the same annual academic goals with minimal variations recorded for each of the last four years. No skills of daily living goals, recreational goals, physical education goals or vocational goals were recorded in any of the case records reviewed by Commission staff. A graphic example of the lack of learning incentive pervasive at the Arlene Training Center is lunchtime, where place settings consisted of only a plate and a tablespoon. Chow mein was served.

Summary of Findings

Programming efforts on behalf of the children in the private residential schools for the mentally retarded selected by this Commission for review are, for the most part adequate. Some programs are exceptional in the

individualization and precision of instruction. Cobb Memorial School, in its program for young children, and Upstate Home for Children are examples. In addition, particular aspects of programs deserve mention:

-- the use as reported by staff of community resources and volunteers to augment the recreational activities at Margaret Chapman School;

-- the multiplicity of evening activities available to residents of the Rhinebeck Country School;

-- the inclusion of the child's parents as responsible members of the treatment team at Rhinebeck; and

-- the implementation of work as therapy philosophy, in the hope of fostering self esteem and responsibility, as practiced at Rhinebeck Country School.

Exceptional programming efforts on behalf of developmentally disabled adults were noted, especially at Camphill Village, where purposeful work of villagers and co-workers alike is essential to the success of the community. The challenge of the constructive use of leisure time is being successfully taken up at Crystal Run School where music, ceramics, woodworking, sewing and horticulture programs are reportedly available evenings and weekends.

Serious program deficiencies exist at several of the selected schools. These include:

-- the lack of definition in behavioral objectives in records reviewed at Hebrew Academy for Special Children;

-- the lack of vocational training and employment opportunities at Greenwood Rehabilitation Center and Arlene Training Center; and

-- the lack of meaningful goal identification and progress notes at Greenwood Rehabilitation Center.

Chapter II
ENVIRONMENT

Paralleling the contrasts in programming are stark contrasts in the living environments of the residents of the private schools. The schools show various levels of success in translating into reality their understanding of the power of the prepared environment to habilitate and teach.

Environments for Growth

As a general rule, the children's environments reflect more careful attention than those of the adults, but this is not always the case -- Camphill Village proving the exception. The pastoral setting of this cluster of shops and homes (each housing six to eight villagers and several co-workers) is reflective of the philosophy that supports this community. Even the architecture of the homes and main meeting and entertainment area, Fountain Hall, is carefully considered in a conscious attempt to incorporate a sense of serenity. The 18 homes at the Village are simple, comfortable and well cared for by co-workers and villagers. Each person is responsible for his own room. Mealtime and general housekeeping chores are shared.

A magnificent outdoor environment likewise enriches the lives of residents of the Rhinebeck Country School. The grounds are beautifully maintained and were decorated with corn husks and pumpkins at the time Commission staff visited in the fall. This same careful attention is evident in the female dormitory area. Twelve children compose a group and share four bedrooms. All of the bedrooms, baths and common rooms were neat, clean and attractive. When an adolescent has progressed enough that discharge is being considered

within the next year, the youngster is given the option of moving into the Honors Dorm. (Presently this option is only open to females. An honors dorm for young men is in the planning stages.) This is a lovely one-family cottage that can accomodate about six residents. The girls live there with one housemother. They take total care of the house and prepare all of their morning and evening meals. An invitation to dinner here is accepted proudly from administrative staff who enjoy bringing their families along to share mealtime with the residents.

The male residents at Rhinebeck do not share in as carefully attended environment. Both the private and common spaces in the boys' dorm lack decoration and individualization. The bedrooms appeared crowded and cheerless.

In a similarly pastoral setting but in full view of the Helderberg Mountains, Cobb Memorial School, serving 25 children, also displays an attention to environment that recognizes its potential as a growth agent. Each bedroom shared by three to four students is attractively decorated with matching bedspreads and draperies. The residential area also contains two attractive dayrooms -- one for younger children, equipped with well-maintained and invitingly displayed Fisher Price toys, and the other, for older youngsters, equipped with board games, TV and stereo.

Perhaps the tale of the drooling child best illustrates the careful attention to the environmental needs of the children that is a hallmark of this institution. Because of the severity of her drooling, it was necessary for a young girl to wear a bib which could be changed several times a day as it became necessary. The housemother sewed "bibs" (rectangular pieces for the front and back connected with thin straps -- similar to the sandwich cards a picketer

wears) using the same material as the uniform that all the girls wear. Thus, the child who needed a bib suffered no loss of personal dignity stigmatized by an appliance worn only by babies -- her bib was nearly invisible.

The residents of Upstate Home for Children share with the children at Cobb that careful individualized attention to their needs that characterizes the two institutions. The determination of the staff at Upstate to create as homelike an atmosphere as possible has resulted in a facility that vibrates with individuality. A tour of the residence reveals bedrooms that reflect the hobbies and heroes of the occupants. Bedspreads and draperies from Snoopy to Superman, record players, radios, model cars and kitten posters, add color and personality to individual rooms. Common rooms are clean, bright and furnished with attractive homelike furniture.

The exterior of the main building and adjoining cottages of Greenwood Rehabilitation Center in Ellenville, New York, pleasantly complement the rural setting of this large facility for mentally retarded and developmentally disabled adults. Along the meadow and treed landscape for hiking and picnicking, a swimming pool and courts for various games provide extensive outdoor recreational opportunities. The main building houses a large day room (formerly the lobby of the hotel), a dining room, kitchen, administrative and nursing offices, and bedrooms for a limited number of residents. The remainder of the residents live in cottages and a new dormitory (completed in 1973) on the grounds. The residents of the new dormitory enjoy a clean and tastefully decorated environment. The various cottages offer attractive, individualized settings.

Environments that Fail

Unfortunately, not all residents of private schools enjoy clean and attractive surroundings. A case in point are the children and lower-functioning adult residents of Margaret Chapman School living in Sherman Hall. A tour of this building reveals bedrooms that emerge from each side of a dark concrete corridor narrow enough that an adult walking down can touch both sides at once. Exposed pipes travel the length of the corridor on the first floor. Bunkbeds, some with peeling paint, assorted nightstands, and newly-purchased wardrobes furnish the children's rooms. The extremely small lounge used by the children has no rug on the floor and is sparsely furnished with plastic molded furniture and a wall-mounted television. No personalizing items were present in any room and toys were stored in a padlocked wooden box.

Problems persisted in the bathrooms and dining areas as well. Bathrooms lacked soap and adequate supplies of toilet tissue. Doors on the toilet stalls were missing and tiles were pulling away from the base of the toilets. The kitchen and the dining areas are small and unsightly. The floors were dirty and the smell of garbage was, at the time of the Commission's initial visit in October, almost over-powering.

An additional area of concern centers on the placement of a woman who is nearly totally bed-bound (spending 2-3 hours a day in a wheel chair) on the above-ground level of Sherman Hall. Since moving this resident takes the work of two aides and evacuation from the building demands the negotiation of a flight of stairs, the placement of this woman presents a potentially serious problem should the real need to evacuate expediently occur. Margaret Chapman staff members have documented their considerable efforts to secure

an alternate living arrangement for this resident. However, the client's lack of language has complicated the search for a nursing home placement.

Brian Hall is home for higher functioning residents at Magaret Chapman and is a more modern building than Sherman Hall. Bedrooms circle the perimeter of a common lounge area. The rooms are carpeted and furnished appropriately with the bedrooms adjoined by closets and bathrooms. Each resident is responsible for his own laundry and for tidying his bath and bedroom. However, some residents lack either the ability or the supervision necessary to maintain their rooms at an acceptably clean level. In one bedroom into which a resident invited Commission staff, the unmade bed exposed sheets that were filthy. The odor in the bedroom and bath was pervasive and unpleasant.

Particular residential areas within New Hope School show deficiencies similar to those noted above in Brian Hall at Margaret Chapman School. As the director at New Hope pointed out, "A hotel always presents problems with homelike environment." This is most apparent in the dormitory area.

Assignment to one of the eight dormitory areas is determined by sex, level of functioning and medical needs. Staffing levels are determined by these variables as well. A staffing ratio of 20 residents to three staff provides the closest supervision, while one staff to 16-20 residents is the most common pattern and is found on four of the units.

Each bedroom contains a closet, two beds, chests and chairs and every two rooms share a bath. Many of the rooms contain radios and TVs or stereos owned by the residents. Two small, sparsely furnished lounges are available for 40 women. Staff volunteered that funds have been allocated for the purchase of some new furnishings, although, they maintain, residents prefer to congregate in each other's rooms.

The men's residential area is similar to the one described above. All bedrooms open onto one long corridor; lounge areas are small and inadequate; and staffing is variable. The particular rooms that Commission staff toured in this area showed significantly diminished attention to housekeeping and hygiene concerns. A number of beds were unmade; others were made but the sheets were dirty and grey and trailing on the floor; some pillow cases were missing; dirty laundry was on the floor; and the bathrooms and bedrooms were foul smelling. Staff explained that more attention is presently being paid to instructing residents in how to maintain their personal environment. An educational staff person is spending ten minutes each morning with each of the residents who cannot make his bed.

While New Hope has initiated corrective action, the adequacy of that action in terms of its scope and allocation of personnel resources is questionable. It is assuredly true that bed-making is problematic and consequently should be targeted for corrective actions. However, it appears unlikely that given the level of staffing, 1:16 -- 1:20, the more comprehensive issues of general cleanliness and the education and training of the residents in the related skills can be adequately addressed.

The South Fallsburg campus of Crystal Run School and the Greenwood Rehabilitation Center are both converted hotels in the Catskill resort area of New York State. Both facilities share the problems inherent in the use of older hotels as long-term residential settings, i.e.; insufficient lounge space for small groups of residents, inadequate floor and closet space in bedrooms serving two or more residents. Additionally, the age of both buildings contribute substantially to the need for or replacement of flooring and bathroom fixtures and refurbishing in general.

At the Middletown campus of Crystal Run, Commission staff toured a recently constructed "semi-independent" dorm which was scheduled for completion in December 1981. The unit will house 32 residents in semi-private rooms. The furniture being placed in the residence at the time Commission staff visited promised to make the dorm attractive and inviting.

The Hebrew Academy for Special Children, likewise, presents serious environmental deficiencies. This converted hotel is the total indoor environment for the 36 adult residents. The sheltered workshop in which all the residents are employed occupies the basement. The communal dining room, living area, kitchen, offices and women's bedrooms are on the main floor. The second floor houses the men's bedrooms and nurse's office.

The common areas were dirty and markedly unattractive. The furniture was old and mismatched, the floors were stained, and rugs and linoleum needed replacing. The long dining tables, covered with faded plastic tablecloths, sentinelled by well-used flypaper and ringed by an assortment of metal and wooden chairs, is the exemplification of the lack of care shown the environment. Bedspreads were in evidence in only the first bedroom Commission staff toured. Personal TVs, radios, and record players were conspicuously missing. The three residents of each bedroom are responsible for making the beds, tidying the room and keeping the bathroom which adjoins each bedroom clean. Maintenance is responsible for vacuuming the carpeting, which reportedly is soon to be replaced in bedrooms, hallways and common rooms, and for scrubbing the bathrooms. Several of the bathrooms were in need of repairs. The flooring was cracked and the fixtures old and stained. The first floor bathroom was filthy.

The kitchen, in sharp contrast to the rest of the facility, reflected caring attention. All of the utensils in view were clean, the stove was greaseless and the refrigerator was well-stocked, clean and all food was covered.

Residents at the Arlene Training Center enjoy an environment distinctly superior to that of Hebrew Academy and Margaret Chapman. The limitation in the environment at the Arlene Training Center is its total lack of challenge and stimulation and the close confinement that it forces on the residents.

The Arlene Training Center is located in a three-story private home in a residential section of Brooklyn where one-family homes sit closely together separated by narrow driveways. This 36-year old institution is home for 16 residents. Additionally, four day students join the residents daily for programming.

The ground level floor houses the kitchen and two large office/living room combinations. These rooms are decorated with knick-knacs, family photographs, mirrors and wall plaques. Residents are allowed to use these rooms when their families visit. The residents' bedrooms (six) and baths occupy the second floor. Three of the six bedrooms have no direct access to the hallway. The beds in each room are covered by identical bedspreads which match the drapes. Housekeeping is excellent: all rugs are vacuumed, furniture dusted and bathrooms cleaned. The bedrooms and bath for the child care staff comprise the third floor. The basement area contains a room that doubles as classroom, lunch room and recreation room plus several other small rooms which serve as offices.

A cement rear yard is the accessible outdoor environment. According to the Director, clients are allowed to leave the house and yard only when accompanied by a staff member. The purpose of this rule is to ensure "good relations with the neighbors."

Summary of Findings

During their visits, Commission staff found a number of environments that please and nurture. This was especially true of the outdoor environments of Cobb Memorial School, Camphill Village and Rhinebeck Country School. Likewise, some indoor environments invited care and attention from the residents and reflected the care and attention of the staff. These included Cobb Memorial School, the Upstate Home for Children and Camphill Village.

Sadly, both child and adult residents of certain schools live in environments that do not support their growth. Notable among these are:

(1) Margaret Chapman's Sherman Hall's exposed pipes, peeling paint, unappointed and damaged bathrooms, uncarpeted lounges and non-accessible toys;

(2) New Hope Rehabilitation Center's lack of adequate attention to the apparent need of clients for instruction in or motivation to maintain their private living quarters; and

(3) Hebrew Academy's inadequate furniture, old and damaged bedroom furnishings, peeling paint, and unsanitary bathrooms.

Chapter III
ADMINISTRATIVE CONCERNS

In the investigation of complaints received by this Commission, the results of several of which appear in published reports entitled In the Matter of Cheryl J.; An Investigation of Selected Incidents at Otsego School; and Profit vs. Care: A Review of Greenwood Rehabilitation Center, Inc., the role of administrative competency in the review of untoward incidents and the supervision of the medically-related activities has figured prominently. Perceiving the issues of internal monitoring, the timeliness and thoroughness of mandated physical examinations, medication dispensing procedures, nursing coverage, and training in life saving techniques to be critical to the quality of life of residents of the private schools, Commission staff undertook a review of these issues at the selected schools.

Again, the striking feature of this review proved to be the degree of variability among the schools in the execution of their responsibility to monitor these matters. The functioning of the Incident Review Committee is a case in point.

Incident Review Process

As the internal monitoring mechanism designed to systematize and coordinate the investigation of unusual occurrences in an institution, the special review or incident review committee remains an essential component of quality assurance. Title 14 New York State Compilation of Codes, Rules and Regulations, Part 81.5, requires the committee meet at least quarterly and investigate all deaths, assaults, escapes, injuries, allegations of abuse

and medically related incidents for the purpose of preventing their recurrence and to maintain written records of its deliberations. At each school Commission staff asked to review the minutes of the two most recent committee meetings and spoke with directors or their designees to elicit their perceptions on how well the incident review process works at their respective facilities.

As noted earlier, the recurrent theme of significant variability among the schools again surfaced. Particular institutions expended considerable staff time and energies monitoring the incidents within their walls. Other institutions used the special review committee meeting as a case conference for a selected client or as a staff meeting.

Margaret Chapman School is singular among the private schools for the thoroughness of its incident review system. The Quality Assurance Director reads all incident reports and all three shifts of nurses' notes each morning to be sure an incident has not been missed. She then has the responsibility of initiating an investigation into all major incidents and of amplifying any reports that are inadequate. She must ensure that all reports are forwarded to the Office of Mental Retardation and Developmental Disabilities and the Incident Review Committee which meets every two weeks. Emergency meetings of the Committee are called when there is the possibility of abuse or when an occurrence has immediate impact on the entire student population, such as the outbreak of a contagious disease. Parents are notified of all major incidents. They are also notified of minor ones if that is their expressed desire. According to the Quality Assurance Director, staff have received extensive in-service training about the need to report any occurrence out of the ordinary as an incident. A review of the minutes of the Review Committee for several previous months by Commission staff did, in fact, reveal that such minor incidents as a

child bumping into a table are reported. Major incident reviews contained a full narrative and investigation. All incident reports reviewed delineated recommendations, where appropriate. It was noted by the Program Director that all team leaders must read and sign all recommendations and discuss them with appropriate staff to ensure their implementation.

In contrast, Commission staff found considerably less vigilence being exercised in the investigation of incidents at both Hebrew Academy for Special Children and New Hope Rehabilitation Center. At New Hope, examination of the minutes of the most recent Review Committee meetings showed that one entire meeting was taken up with a discussion of the behavior and possible placement of one resident. Additionally, the minutes showed that neither the director nor associate director was in attendance at either of these meetings, in violation of attendance rules. Consequently, the program director chaired the meeting. When questioned about the type of occurrences that would be considered incidents, the program director listed as examples medication errors, long-standing problems of particular clients, and suicidal gestures.

The program director then related the details of such an incident. While distributing medications, a staff member dropped a pill and, despite searching the carpeting for several minutes, was unable to find it. Several hours passed and another staff member, quite accidentally and totally unaware of the prior events, found the pill in the hallway and returned it to the nurse. Commission staff asked to see the incident report that was filed, reasoning that the pill was still missing after the initial search, and quite possibly could have been found and ingested by a

resident. The Commission further assumed that the program director, in offering these events as illustrative of a medication error, would consider the matter reportable. Commission staff were told, however, that no incident report was filed because the pill was finally found.

Commission staff identified similar discrepancies in the operation of the Incident Review Committee at Hebrew Academy for Special Children. Rather than the review and investigation of incidents, the committee case conferenced around such needs of particular residents as whether laxatives should be discontinued. While multi-disciplinary team meetings focused upon the needs of a particular resident are not only appropriate but essential to comprehensive treatment, the choice of the Incident Review Committee as this forum is unfortunate as it reduces the attention to incidents and purveys to the staff a diminished regard for the incident review process.

Medical Issues: A Limited Review

In addition to a review of the incident reporting process, Commission staff undertook a limited review of the medical delivery systems operating in the selected schools for the purpose of assessing a second measure of the quality of care provided the residents. This review focused on three areas: the timeliness and thoroughness of physical examinations, the procedures for the administration of medication, and the ability of the facility to meet medical emergencies. Commission staff observed no actual patient care. A record review, examination of cardiopulmonary resuscitation (CPR) training schedules and interviews with administrators and nurses provided information.

Physicals: True Preventive Medicine? Generally, the schools met the requirements of NYCRR Part 81.6(d)(1)(i) and provided adults with an annual physical and children with a physical exam semi-annually. Some schools used the services of local clinics and hospitals. (The Mental Retardation Institute in Valhalla, New York, is particularly helpful to area schools, providing multi-disciplinary assessments and treatment.) Other schools contract with a physician to come to the school and perform the exams. This arrangement, whereby the examinations are performed at the school rather than in a clinic or physician's office, is practiced at Upstate Home for Children, New Hope and the Hebrew Academy. The caliber of these examinations, judged by the physical examination forms included in the residents' case records, varied considerably among the three institutions.

Both case records at Upstate revealed thorough physicals and appropriate requests and procurement of laboratory studies and consultations. Prescriptions were updated monthly, and weekly nursing notes completed the record. Similarly, the medical management of the two residents selected for review at New Hope Rehabilitation Center was excellent. Although the annual physicals were performed at the facility, blood work and EEGs were done preparatory to these exams. Additionally, consultations with a cardiologist and a gynecologist were requested by the examining physician. These were obtained within a reasonable time and the reports were attached to the physical. One of the residents selected for review is maintained on Digoxin .25 mg q.o.d. and serum levels were appropriately drawn every three months.

The serious efforts to use the physical exam as an effective tool in detecting disease evidenced at Upstate Home for Children and New Hope Rehabilitation Center did not

extend to the Hebrew Academy for Special Children. There the completed forms reviewed by Commission staff noted only a blood pressure reading under the section for vital signs. No gender specific examinations were provided. This is in contrast to previous years when clients traveled to the physician's office for their physical exams.

The deficiencies noted at the Hebrew Academy are dwarfed by those found at the Arlene Training Center in Brooklyn. In an attempt to review medication practices at the school, Commission staff reviewed four case records, medication charts, medication administration sheets and actual medication bottles.

No doctor's orders or copies thereof are contained in the case records. The medication chart, dated September 1981 and posted in the principal's office and inside the door of the locked medication cabinet in the kitchen, showed Anna Bell's* medications as follows:

10/10/77 Haldol 2 mg SS A.M. (SS=1/2)
SS noon

9/8/77 Chlordiazepoxide (Librium)
5 mg 1 tab 3X daily

The bottle that actually contained the Haldol read 2 mg 3X daily. The medication administration sheet recorded the dosage as 2 mg A.M. and, according to the child care worker who distributes medications, this is what she actually gives Anna Bell.

Further examination of the medication practices revealed additional problems. A bottle labeled phenobarbital was found in the cabinet. In checking the resident's name against the sign-out book, Commission staff found that the medication had not been dispensed in over a month. When

*A pseudonym.

questioned as to why, Commission staff were told that Bruce Rorey,* the child whose name appeared on the bottle, had been at the school for respite a month earlier and had not been back since. Examination of the contents of the bottle showed that, in fact, it was not phenobarbital at all but rather Thorazine which, according to the child care worker, was prescribed for Armando Seitz.* (Phenobarbital is a small white pill. Thorazine resembles a mustard-colored M&M.) When questioned regarding the practice of putting medications into mislabeled bottles, the worker advised that she does this often when she has to empty a bottle in order to send it to the pharmacy for a refill.

The medication administration book likewise showed significant departures from standard nursing practice. Regardless of the frequency of distribution or the number of medications a particular child receives, the child care worker initials the record once in the morning. On the day Commission staff visited, even this system was not working -- at 11:30 a.m. no medications had been signed out even though they have been given at breakfast.

The lack of a recognizable and verifiable system of medication administration at this school, coupled with the lack of a second physical exam for residents under 21 and the absence of dental exam records, presents a health-impairing and potentially life-threatening problem. The fact that the entire system of medication administration operates without any copies of doctor's orders and that the registered nurse employed by the school has taken no responsibility for the supervision and oversight of medication administration represents substantial deviations from accepted medical practice.

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*Pseudonyms.

Nursing Coverage and CPR Training. The Upstate Home for Children, Crystal Run, New Hope and Margaret Chapman have made significant efforts to insure the safety of their residents through staff education in CPR and other life saving techniques. School policy at Margaret Chapman requires that all direct care and professional staff receive CPR and Basic First Aid certification within 90 days of employment. At Crystal Run, staff is trained in CPR and refresher courses are offered regularly. On the day that Commission staff visited New Hope, several staff members were busily studying for the CPR refresher session to be held that same evening on their campus. These commendable efforts deserve mention, particularly since many schools have not been as successful.

At Greenwood Rehabilitation Center only twenty staff members with direct client contact had been trained in CPR at the time of the Commission's visit in December 1981. It is important to note that one of the specific recommendations made by this Commission in an earlier report identified the need for Greenwood to "immediately initiate training for all direct care staff in techniques of cardiopulmonary resuscitation and first aid." In response to this recommendation, OMRDD expressed its intention to implement this procedure and revise its policies and regulations to require such training. Greenwood has failed to give this training priority treatment.

This is not to say that Greenwood Rehabilitation Center has not taken recent measures to safeguard the well-being of its residents. Presently the facility employs an emergency medical technician (EMT) who lives on the grounds and is "on call" 24 hours a day. In addition, approximately 18 other staff members are CPR certified according to information supplies by the school. While the availability of such a

specifically trained professional is a development likely to significantly reduce the likelihood of the recurrence of a choking incident resulting in tragedy, it does not negate the need to provide CPR training to all direct care staff.

Summary of Findings

Commission staff focused its efforts on four areas judged to be indicators of administrative attention to the quality of care within the institution: incident review, the procurement of timely and complete physicals, medication administration procedures and training in life saving techniques.

Margaret Chapman School is particularly notable for the professional approach it brings to the review of incidents. On the other hand, incident review at Hebrew Academy for Special Children and New Hope Rehabilitation Center clearly suffers from a lack of clear definitions and sense of purpose for the review committee.

Attention to the delivery of adequate medical care varied considerably among the selected institutions. New Hope and Upstate Home for Children showed particular care in their procurement of physicals and related laboratory studies. The physicals performed at Hebrew Academy, however, appeared incomplete, giving very little specific data on each resident selected for review. The medication administration procedure at the Arlene Training Center that operates in the total absence of any doctor's orders or copies thereof is a serious problem that has persisted despite its citation in the certification report made by OMRDD and verbal counsels from the certification team.

Similarly, despite assurances from OMRDD that Greenwood Rehabilitation Center would undertake the training of all direct care staff in life saving techniques, Greenwood has been unable to accomplish this. This is in direct contrast to Upstate Home for Children, Crystal Run School, New Hope and Margaret Chapman, all of whom have made significant efforts to certify all direct care staff in CPR. The employment of an emergency medical technician at Greenwood, while not negating the need for this training, does reduce the risk to the residents.

Chapter IV

MONITORING THE SCHOOLS: THE FOCUS OF MANY EFFORTS

In the course of visiting the schools and interviewing their directors, Commission staff were readily able to identify school-specific environmental and programmatic issues, but soon systemic problems also surfaced. Perhaps the most global, and consequently the one most fraught with ramifications, is the issue of the position of the private residential schools within the State's continuum of care for the mentally retarded.

Paradoxically, while the schools grew in response to a gap in the services available to the mentally retarded, today these schools, with rare exceptions, are isolated institutions, disconnected from the mainstream of service delivery to the mentally retarded and developmentally disabled. Complicating this isolation is the fact that the schools are the province of a number of oversight agencies and are receiving funding from a number of sources.

The State Education Department (SED) oversees educational programs for the children under 21; OMRDD monitors the residential programming for all clients; and the Health Department checks kitchen and dining facilities. SED, the Department of Social Services, and OMRDD (through the Chapter 720 provision) are funding sources. With the oversight responsibility spread among several agencies, there is no one staff or agency that has a comprehensive picture of the quality of life within the schools. Additionally, since OMRDD and SED each operates with its own set of rules and regulations, items identified as needs by one agency may not be considered essential and consequently are not funded by the second agency. A case in point is the

citation by OMRDD that Upstate Home for Children needed an additional social worker. SED reportedly viewed the additional staff as a luxury and would not include the position in budget calculations.

While the schools on the one hand have to deal with separate oversight and funding agencies, they rely almost exclusively on the Private Schools Unit at OMRDD's Central Office for technical assistance. Consequently, the needs and concerns of the schools often do not reach the appropriate forum, further reinforcing the schools' perception of themselves as islands of service. While they must depend upon the long-range planning of the County Service Group to provide transition services, accommodations, and programs for residents in the community, the schools communicate almost exclusively with the Private Schools Unit which is ill-equipped to grapple with placement issues often peculiar to a geographic area.

Illustrative of this point is the case of Pearl Farmer,* a non-ambulatory resident of the Margaret Chapman School. The school has been contacting nursing homes in an effort to find a more suitable living situation for Ms. Farmer. To this end, the director of the school told Commission staff, she has asked for assistance in this placement. The Private Schools Unit of OMRDD, operating out of Albany, has been unsuccessful in assisting the school. It is the centralized nature of this unit which severely undermines its usefulness as the principal resource for technical assistance available to the private schools. Compounding this situation is the fact that the unit is comprised of three persons who are responsible for all the private schools in the State. Consequently, Margaret Chapman continues to assume full responsibility for finding a suitable placement for Ms. Farmer who is presently able to

*A pseudonym.

spend only 2-3 hours a day in a wheelchair. She is confined to bed the remainder of the time with a nurse's aide assigned exclusively to her on a 24-hour a day basis.[2] In addition to ill residents, a bottleneck of well residents ready and, in some cases, anxious to leave the restriction of the private school setting for the relative freedom of the community residence has developed.

However, it is not only the multiplicity of interactions of State agencies and departments with jurisdiction over them that is problematic for the private schools. Difficulties arise in response to internal structures or lack thereof within OMRDD. Although New York State has had regulatory responsibility for the private schools since their inception, it is only recently and in large measure a response to investigations performed by this Commission, that the Office of Mental Retardation and Developmental Disabilities has increased its vigilance of the schools. Policies, procedures and regulations are still incomplete, with such significant issues as discharge policies still in the process of being formulated. Having been neglected for so many years by OMRDD, the private schools have come to expect ineffectual regulation, inconsistency in the interpretation of regulations, and inaction in the monitoring of plans of correction.

A comprehensive set of OMRDD rules and regulations governing private schools, which is all-encompassing and addresses the spectrum of operations of private schools, is sorely needed. School administrators have pointed out, as an example, that they have no idea which regulations they are to follow concerning discharge procedures. Some schools are using guidelines for community residences, some for developmental centers, and some lacked guidelines entirely.

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[2]Ms. Farmer died at St. Agnes Hospital in Westchester on August 30, 1982. The cause of death was listed as cardiopulmonary arrest.

As an example, Camphill Village operated without discharge policies until a recent crisis forced OMRDD and the administrators of the facility to jointly establish discharge criteria and procedures.

Incident review procedures are another case in point. Margaret Chapman conducts incident review according to OMRDD guidelines distributed to the school during an unannounced visit. However, these guidelines, according to Margaret Chapman administrators, have not been shared with the other private schools. Consistent with this information are the statements of staff from several schools indicating confusion about incident reporting procedures.

In addition to the lack of a comprehensive set of rules and regulations, inconsistency in the application of existing standards is often cited by the schools as an exasperating and unjust practice. For example, the director of the Rhinebeck School spoke of his annoyance at certification personnel who told him he had to remove bunkbeds from the "honors home," a small house on the grounds of Rhinebeck designed to serve as a transitional living setting for young women prior to discharge. This would have had the effect of dismantling one aspect of his program that is unique among the schools Commission staff visited, innovative and particularly successful. On the other hand, Margaret Chapman's Sherman Hall, which houses approximately 90 children and adults, has numerous bunkbeds. When questioned about this, the residence director there indicated to Commission staff that she had never been told that bunkbeds were not allowed and that she knew of no such restriction. A staff member in OMRDD's School Certification Unit informed Commission staff that there is no directive regarding bunkbeds and that inspectors may use their own judgment.

In a similar circumstance, New Hope, which serves 148 residents, was cited in its certification report for assigning specific places at meals for the residents. (Residents are grouped according to diet and eating skills.) The Arlene Training Center, serving 16 residents, also assigns seats at mealtimes. However, unlike New Hope, the Arlene Training Center was not cited as being in violation of the "home-like atmosphere" clause in the regulations.

While these examples of inconsistencies may be particularly annoying to school administrators, other examples have a far more serious impact. The certifiction report on Rhinebeck Country School, for instance, cited the "boys dorm" (housing 37 clients) for violation of the square footage regulations while the latest certification report, dated December 11, 1981, made available to the Commission by OMRDD had no such citation for Margaret Chapman's Sherman Hall which houses 85 residents in poorer conditions.

The Certification Process

The OMRDD certification process has several features that commend it. The inclusion of an engineer in the certification team promotes the kind of attention to structural considerations that are beyond the capabiliites of most mental health professionals. The format for recording deficiencies on the certification report is clear and concise. The nature of the violation is described and often referenced with the regulation number from the standards, and the action required to bring the facility into compliance is clearly stated. In cases where the members of the inspection team feel they want to make recommendations to better the quality of life in a facility above and beyond compliance with the minimal requirements of the regulations,

these are made in the report but are clearly separate from deficiency citations. The identification of general facility strengths as well as weakness, serving as introductory material to the body of the report, significantly contributes to the "total picture" the report presents.

Nonetheless, in its application, the certification process is seriously flawed. Inspection teams make two or possibly three visits to a school and issue a certification report. The school has ten days to make any factual corrections in the report and thirty days in which to respond with a plan of correction. If the plan of correction is acceptable, the school is recertified. It would seem that no matter how seriously deficient the environment is, or how far into the future the plan of correction would project, as long as the plan is forthcoming the school is recertified. Obviously, the seriously deficient conditions in Sherman Hall have existed for years, yet on July 1, 1981 the school was granted a two-year certification.

Medication practices at the Arlene Training Center illustrate a second flaw in the system -- the lack of followup. In late December 1980 and early January 1981, the certification inspection team made two visits to the Arlene Training Center. They found the same highly irregular medication practices that Commission staff witnessed almost one year later. This was the case despite the following entry in the certification report forthcoming from the December-January visits:

> It should be noted that inconsistencies with regard to medication dispensation and control were discussed with Arlene Center staff at the time of our visit and the need for immediate corrective action stressed.

However, there is no record of followup and, as noted earlier in this report, there has been no improvement in medication procedures.[3]

Supplemental Funding

For those schools which serve adults (aged 21+), the need to be considered "in substantial compliance" with the terms of its operating certificate and all rules and regulations that relate to the operation of the facility by OMRDD is particularly strong since the passsage of Chapter 720 of the Laws of 1979 (N.Y. Mental Hygiene Law §§13.15, 13.16 and 31.07). This statute allows the Commissioner of the Office of Mental Retardation and Developmental Disabilities to contract with providers furnishing services to residents of OMRDD licensed schools for the mentally retarded, when such residents are over the age of 21 and are eligible to receive funding pursuant to N.Y. Social Services Law §209 (SSI provisions) in specific dollar amounts above the monthly private school SSI rate. This law expressly adds the condition that the school be "in substantial compliance" in order to receive the additional funds. A limited review of the status of Chapter 720 schools show questionable and, in one instance, extremely problematic interpretation of the "substantial compliance" clause.

Crystal Run, New Hope, Hebrew Academy for Special Children and Margaret Chapman presently comprise the schools receiving Chapter 720 funding. On the basis of the Commission's review of these schools, it is not unreasonable to assume that substantial compliance is gauged by some criterion other than the severity and impact of deficiencies.

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[3] Profit vs. Care: A Review of the Greenwood Rehabilitation Center, Inc., published by this Commission in March 1981 details another example of numerous and serious deficiencies existing for years with neither correction nor follow-up.

Environmental deficiencies, for example, regardless of their severity, appear to be discounted as long as a plan of correction is forwarded to OMRDD. Margaret Chapman and Hebrew Academy are cases in point.

Margaret Chapman, as pointed out earlier in this report, despite severe environmental deficiencies that include inadequate private and common space, inadequate furniture, bathrooms in need of major repairs, unsanitary and inadequate dining areas, has been granted Chapter 720 funding having been judged to be in substantial compliance with OMRDD rules and regulations which clearly mandate an environment that is adequate in size, in good repair adequately furnished and clean. A notation appearing on the most recent certification report made available to the Commission leads one to the conclusion that OMRDD granted 720 funding status theorizing that the infusion of added revenue will make the projected renovations to Sherman Hall possible.

Hebrew Academy, on the other hand, provides a prime example of an institution which has been cited repeatedly for the last nine years for environmental deficiencies which persist year after year. Although a plan of correction is filed by Hebrew Academy with the OMRDD, the substandard conditions persist and are recited.

Summary of Findings

An ironic shift has taken place within the last decade which has seen services for the mentally retarded, with a network of State and private residential, day treatment and vocational opportunities, flourish with little or no attention to the students in private schools. This has effectively left the institution which was created as an option

for parents with developmentally disabled children, clinging in many cases to restrictive programming and vocational options. Additionally, the lack of a close association between the private schools and their respective County Service Groups has encouraged regional planning that has largely ignored the needs of the residents of the schools.

In addition to problems generated by the isolation of the schools from the mainstream of the service delivery to the mentally retarded and developmentally disabled population, the schools are hampered by the absence of a comprehensive set of rules and regulations governing their operation. Lacking regulations regarding such essential operations as incident review and discharge planning, the private schools follow procedures adopted for other facilities or operate without any point of reference on these matters until a crisis erupts. Such was the case with discharge procedures at Camphill Village.

While on the one hand, the schools suffer from a lack of specific procedures, they are also severely encumbered by the related and overlapping roles of State agencies entrusted with regulatory and/or funding responsibility. There has been too little attention paid to the formulation of uniform policies and expectations by the governing agencies. This unfortunate combination of a lack of a comprehensive set of regulations plus differing expectations brought to the schools by the various oversight agencies has undermined the legitimacy of regulation and enforcement. Actual enforcement power is exercised idiosyncratically. The present system discourages the administrators of the private schools from seriously heeding the recommendations of the oversight agencies, since it is equally likely that they are hearing the whim of a State bureaucrat rather than the recitation of a carefully formulated and adequately promulgated policy.

The lack of a comprehensive set of regulations, that clearly identifies those minimum standards necessary for compliance, has become a critical issue since the initiation in 1979 of Chapter 720 funding. This law mandates that eligibility for the extra funding must be preceded by a determination that the facility is "in substantial compliance" with the rules and regulations governing private schools. The fact that schools such as Margaret Chapman and Hebrew Academy are receiving these funds while still plagued by serious environmental problems highlights the need for a standard of minimum acceptability.

Chapter V
CONCLUSIONS AND RECOMMENDATIONS

The three month review of the private schools undertaken by Commission staff in the fall of 1981 brought to light serious deficiencies in several schools. These included significant environmental deficiencies such as those at Hebrew Academy and Margaret Chapman; marked departure from standard medication practice as seen at the Arlene Training Center; and suboptimal programming and assessments as evidenced in Greenwood Rehabilitation Center and the Arlene Training Center. While these areas of deficiency cry for remediation, they also point to internal weaknesses in the oversight process that allows such conditions to occur and persist.

The need to coordinate efforts and compile a comprehensive set of rules and regulations from the various oversight agencies is critical. Consistent application of standards is necessary, and the conscientious use of follow-up site visits to insure that corrections are made is a component of the certification process which has been either ignored or proven inadequate and ineffectual when, as in the case of Hebrew Academy, some of the environmental deficiencies cited in the certification report of 1973 still exist.

In addition to problems in the certification process itself, the isolation evidenced by many schools, graphically demonstrated by the schools' inability to access residential opportunities of a less restrictive nature, has led this Commission to conclude that the establishment of closer ties between the schools and the County Service Groups into whose catchment area they fall will ultimately result in treatment

which adapts itself to the changing needs of individual residents as they mature and age.

In view of these conclusions, the Commission offers the following recommendations, prefaced by the acknowledgement that recommendations emanating from findings critical of the operation of the certification team of OMRDD follow a review of work done by individuals no longer in the Private Schools Unit of OMRDD and when the unit was critically understaffed. This Commission understands that the staff members presently in the unit have been working conscientiously to bring all certifications up to date and to set a schedule for regular periodic visits to every school. Additionally, they have met with a group of representatives of the schools to clarify issues of concern to both the facilities and OMRDD. We recognize and encourage these and similar activities.

1. The Commission recommends that all agencies involved with the private schools join in an effort to formulate one set of regulations that govern all certification issues, and that the agencies conduct joint visits and issue joint reports to the maximum extent practicable. The ideal to be strived for is the attainment of a certification process that provides the facility and each of the oversight agencies a comprehensive and integrated view of the quality of life at the schools. Toward this end it is recommended that a task force, consisting of representatives from OMRDD, the State Education Department, Department of Social Services and Department of Health be created for the purpose of designing the consolidation of regulations and oversight activities. We recommend that this body welcome and encourage input from the private schools themselves

and submit periodic reports of its activities and a final report of its recommendations within one year to this Commission, the Commissioners of the affected State agencies, and the directors of the schools.

2. This Commission has cited major environmental, programmatic and health-related deficiencies which, despite their identification by OMRDD, have been allowed to continue for years without correction. It is therefore recommended that OMRDD set reasonable time limits for the implementation of corrective actions and that certification granted to the facility during this correction period be conditional and revoked if corrections are not implemented on a timely basis.

3. To further advance the integration of the private schools into the mainstream of the mental hygiene delivery system, it is recommended that the dual functions of technical assistance and certification presently the responsibility of the Private Schools Unit within OMRDD be divided, with the Private Schools Unit retaining the certification function and the County Service Groups serving as technical advisors. This will enable the certification unit to vigorously monitor compliance issues and the implementation of plans of correction at the schools. At the same time, this will better align the technical assistance needs of the schools and the needs of their clients to the resources available through County Service Groups which monitor and provide assistance to all other mental retardation agencies in their catchment areas.

4. It is further recommended that a needs assessment of the 1,300 persons in private schools be undertaken.

The present and future residential, vocational and educational requirements of this population, especially those residents who are aging and growing enfeebled, should be addressed and planning begun to meet the identified needs.

5. Finally, it is recommended that, for the purpose of determining "substantial compliance," OMRDD develop a system for assigning weight to critical compliance issues. When an oversight agency is faced with the challenge of enforcing a diverse set of regulations which range from requirements concerning maintenance of meeting minutes to requirements concerning substantial life safety and environmental issues, it is imperative that minimal criteria be established which all schools must meet in order to be considered in substantial compliance.

In an effort to correct those deficiencies specific to particular institutions, the Commission offers the following recommendations:

6. Hebrew Academy for Special Children.

The OMRDD report dated May 1980 certifying the facility until April 1982 cited numerous environmental violations (some originally cited as far back as 1973) including unsanitary bathrooms, need for furniture repair, painting and lack of sufficient chests and chairs. Since the facility is presently receiving 720 funding, this Commission recommends that the OMRDD ensure that these funds are used to correct environmental deficiencies and improve the quality of life at the facility. Additionally, a financial audit of the use of the clients' wages and personal allowances is also recommended.

7. Arlene Training Center.

In view of the fact that the seriously deficient medication practices noted during the Commission visit had been cited one year earlier and no corrections had been made, we recommend that the County Service Group give immediate technical assistance to this institution to bring it into compliance with standard medical practice. We request that the County Service Group advise this Commission of the details of the program they establish for the school and of the monitoring procedure they will use to insure its implementation.

The area of programming for the adult residents at the Arlene Training Center remains a serious problem. In an effort to find meaningful vocational training and employment opportunities for this population, the Commission recommends a program review of the Arlene Training Center which considers, in addition to an evaluation of the existing programming, client assessment and placement. The vocational program that is presently in operation should undergo a critical evaluation and the possibility of using community resources should be fully explored.

8. Margaret Chapman.

(a) The environmental conditions in Sherman Hall have been investigated in the past by the OMRDD Schools Unit, the Southeastern County Service Group, Westchester Developmental Center, and this Commission. Although some changes have been made, substantial problems

remain. The Commission recommends that Margaret Chapman be instructed to make non-structural changes in this building. Each resident should have a dresser in good repair and a chair. No child should be in a bed with peeling paint. Toys that are clean, safe, complete and unbroken should be readily available in the lounge used by the children. The lounges should have living room type furniture and rugs on the floor. Decorations and personalizing items should be provided. We further recommend that the County Service Group be charged with the responsibility for monitoring these improvements and that they report to this Commission quarterly on the progress made by Margaret Chapman.

(b) Secondly, the Commission recommends that OMRDD review the plans submitted by the school for the construction of a new dining area and the conversion of the present dining room to lounge space, and if the plan is acceptable, facilitate its movement from plan to reality by whatever means it has at its disposal.

(c) Finally, the Commission recommends that the County Service Group assess the Margaret Chapman population and make substantial efforts to find appropriate alternate living situations for those clients capable of more independent functioning. As residents are moved out of Margaret Chapman, the census in Sherman Hall should be correspondingly reduced and no new admissions accepted.

9. Greenwood Rehabilitation Center.

The Commission recommends that the County Service Group provide Greenwood with technical assistance aimed at providing comprehensive programming to meet the habilitative, social and vocational needs of the residents. In addition, the Commission recommends that the Private Schools Unit at OMRDD monitor closely the programming offered at Greenwood to be sure that it is in compliance with all of the rules and regulations (NYCRR Part 81.6) that govern programs in schools for the mentally retarded.

10. Finally, the selection of appropriate candidates for residency in schools such as Greenwood, Hebrew Academy for Special Children and the Arlene Training Center, where opportunities for community interaction are severely limited, must be undertaken cautiously. The fact that mildly and moderately retarded residents with significant capabilities (e.g., those who can participate in clerical skills classes) are placed in these restrictive environments raises questions regarding the selectivity of the admissions procedures and the rigor with which the institutions seek community contacts and opportunities for work and recreation beyond their walls. This Commission recommends that these institutions undertake a skills assessment of their populations for the two-fold purpose of identifying those residents ready to move to a less restrictive environment and to identify those skills lacking in residents who will soon be ready to move.

APPENDIX A

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 12229

ZYGMOND L. SLEZAK
Commissioner

October 18, 1982

Mr. Clarence J. Sundram
Chairman
Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue
Suite 730
Albany, NY 12210

Dear Mr. Sundram:

I am writing to acknowledge receipt of your letter of September 10th and the accompanying confidential draft document, A Review of Private Residential Facilities for the Mentally Retarded: Their Position in the Continuum of Care for Developmentally Disabled and Mentally Retarded Individuals. I appreciate the opportunity to review and comment on the report prior to its finalization. OMRDD has carefully analyzed the Commission's comments and compared them with our own assessments of the private schools for the mentally retarded identified in the report. The enclosed attachments summarize the analysis we have undertaken and offer comments and clarification to assist the Commission in preparing its final report.

As an introduction to the information contained in the attachments, I wish to outline for you the rationale for the establishment of the Private Schools Unit, our recent activities and present priorities with the private school class of service providers; and OMRDD's reactions to the major recommendations of the Commission's report.

It seems particularly appropriate to address this information to each of the five major components which we have identified in the report: 1. Organizational structure of OMRDD's certification and technical assistance functions; 2. Compliance monitoring activities; 3. The Regulatory base governing private residential facilities and the place of the schools in a "continuum of care"; 4. Observations and recommendations for individual private schools; and 5. General recommendations.

1. Organizational Structure

Approximately twenty months ago, OMRDD began the process of more closely examining the private residential service delivery system in the State. This represented the first time in some five years that OMRDD was able to focus on this group of providers in a systematic way and to redirect available resources from the deinstitutionalization effort for this purpose. A comprehensive review of the status of the twenty private schools located statewide resulted in the establishment, on an interim basis, of a Private Schools Unit in the OMRDD central office. The unit was designed to take the lead in certifying, monitoring and providing technical assistance

to the private schools, both through its own efforts and by utilizing the existing OMRDD organizational structure: County Service Groups, Borough/Developmental Disabilities Services Offices (B/DDSO's) and other central office services (e.g., Health Services and Staff Development). The creation of the unit was seen as the most expedient and effective means of resolving several major issues. In addition to the certification, monitoring, and coordinating functions, these included developing guidelines for uniform application of standards, and revising and strengthening the regulatory base. Further, the need for a coordinated review and analysis of the existing funding structure was an additional factor in the decision to establish the unit.

2. Compliance, Monitoring Activities

Upon establishment, the Private Schools Unit set out to accomplish several specific tasks. As will be noted in the attachments to this letter, where they are more fully discussed, several of the tasks have reached completion points while others are in the process of being implemented. For the purpose of providing an overview, however, I think it is important to outline those tasks at this point:

- Of first importance was the updating of the certification status of each of the schools, including comprehensive assessments of strengths and weaknesses at each of the schools.

- Plans of corrective action are monitored through a schedule of site visitations. Currently, staff visit each school at least four times each year (twice the mandated frequency) and more often with schools having particular problems.

- The Private Schools unit has developed the capacity to monitor and coordinate the provision of technical assistance to the schools, either on the correction of problems relative to certification or in response to specific client-related circumstances.

- OMRDD recognizes that a provider may have to deal with more than one State regulatory agency. In cases like this, there can arise points of ambiguity, as the Commission report has noted, even given the best intentions of all parties concerned. To alleviate this real concern, the OMRDD has initiated steps to coordinate monitoring and technical assistance activities with other regulatory agencies. Additionally, the Office is participating with other state agencies, under the coordination of the Council on Children and Families, in a program information exchange and the development of a uniform set of standards for child care facilities.

- The chapter 720/233 funding mechanism, the subject of two OMRDD reports to the Legislature, has been in place since 1979. Historical data from this program has enabled the OMRDD to evaluate the effectiveness of this mechanism and to formulate Legislative proposals for modifying and strengthening existing laws governing its implementation and its relationship to compliance standards.

3. Regulatory Base and Continuum of Care

OMRDD recognizes that the regulations governing the operaton of the private schools would benefit from a comprehensive revision. To this end, the OMRDD has initiated steps to revise the regulatory base, with the intentions of clarifying expectations for the schools and enhancing the OMRDD's ability to monitor the provision of care.

The current regulatory base (14 NYCRR 24, 25, 27, 73, 77, 78 and 81) contains only the basic requirements for this provider class. The revision process to which I referred earlier in this letter is intended to produce a regulation that would more comprehensively address, among other issues: program standards; individualized treatment planning and implementation; physical plant standards; administrative practices; funding structures; admission and discharge procedures; and the appropriate inclusion of private residential facilities in the continuum of care. As a subset of the regulatory effort, we look toward the initiation of a community development effort which would, in the future, allow for the community placement of clients who would be more appropriately served in those settings.

4. School Specific Observations

The findings in the draft report regarding the ten private school programs surveyed by the Commission, are consistent with the observations of OMRDD staff for the same programs, with clarifications included in Attachment III. The major deficiencies cited in the draft report either have been remedied or are currently being addressed, in accordance with timetables integral to the plans of corrective action which the OMRDD has required of the schools in response to certification inspections.

5. General Recommendations

The general recommendations made in the Commission's report have been addressed individually in Attachment III. Briefly, however, OMRDD concurs that a new regulatory base is warranted. Development is going forward and OMRDD will keep the Commission apprised of progress. It is anticipated that the new regulations will incorporate a system for assigning "weights" to specific requirements, to address the issue surrounding the definition of "substantial compliance" and to further insure the consistent application of standards for which OMRDD is striving. With regard to the environmental, programmatic and health-related deficiencies cited in the draft report, OMRDD has been actively working to remedy existing problems through several means. These include the issuance of time-limited certificates with addenda indicating required actions; the monitoring of plans of corrective action through site visits and correspondence; and the rendering of technical assistance, using the resources at the Office's disposal. In this undertaking, the OMRDD was aware that the process of correcting deficiencies could be lengthy, particularly where physical plant problems were concerned. The course of the agency to deal with this dilemma, however, was consciously chosen. It was seen as essential to move forward with the certification process while providing technical assistance and intensive monitoring, as needed. This course was the one that best respected the interests of the residents at

the schools, acknowledged the positive features of each facility and their good faith efforts to remedy problems and established a firm and clear base for future relationships between the OMRDD and the schools. Finally, OMRDD concurs with the recommendation that a needs assessment for the residents of the schools be undertaken. It is the perception of the OMRDD that the schools themselves are best situated to complete this task, with monitoring and appropriate assistance. The Commission will be apprised of progress in this regard.

OMRDD concurs with the recommendations regarding the organizational locus and mandate for provision of technical assistance and performance of certification functions. As stated earlier, the central Private Schools Unit was established to provide a centralized focus to this class of providers. Its functions were and continue to be of time-limited duration. The unit has been successful in performing the first phase of priority initiatives assigned to it, is ready to undertake a second phase, and has begun the transition of some functions to other units. All of these activities will ultimately lead to certification, inspection and monitoring responsibility resting with the Division of Quality Assurance and with direct technical assistance resting with the DDSOs and County Service Groups.

In order to ensure an orderly and effective transition of various functions relating to the schools, it is planned that:

- Certification and monitoring responsibilities will transfer to the Division of Quality Assurance on February 1, 1983.

- Development of a new regulatory base will remain centralized with the Private Schools Unit and the Bureau of Standards and Procedures, with input from providers. This intent was communicated to the Commission (see Attachment IV, letter from Dr. Otis to Mr. Harmon dated September 24, 1982). Task force meetings have convened and this project has been initiated. Completion will take approximately one year. The Commission is invited to review these draft regulations as they are developed.

- Technical assistance coordinating responsibilities will remain centralized, pending the completion of the new regulatory base and compliance of each school with that base. It is expected that these functions will transition to the County Service Groups and DDSOs subsequent to the implementation of the new regulations.

Enclosed with this letter are four attachments in which OMRDD seeks to provide the Commission with data and reactions to assist in the finalization of the draft report. I should note that in speaking to programmatic, environmental and administrative concerns, the draft report makes many points which the OMRDD finds valuable and with which we concur. Our comments, therefore, in the attachments are meant to clarify and update.

- Attachment I is a chart summarizing the certification status of each school and indicating significant issues of present concern to the OMRDD.

- Attachment II outlines the major activities the Private Schools Unit has undertaken since its inception, indicates the purpose for each activity and briefly summarizes current status.

- Attachment III provides comment in response to specific observations in the draft report.

- Attachment IV is a copy of Dr. Otis' September 24, 1982 letter to Mr. Harmon describing our intent to revise the Private Schools regulations.

I trust that this material, taken together with my comments in this letter, is helpful to the Commission in completing its analysis of the status of the private schools for the mentally retarded certified and monitored by OMRDD.

Sincerely,

Raymond L. Slezak
Commissioner

Enclosures

THE UNIVERSITY OF THE STATE OF NEW YORK
THE STATE EDUCATION DEPARTMENT
OFFICE OF THE PRESIDENT OF THE UNIVERSITY
AND COMMISSIONER OF EDUCATION
ALBANY, NEW YORK 12234

October 8, 1982

Dear Chairman Sundram:

Thank you for providing me with a confidential draft of the Commission's report entitled, "A Review of Private Residential Facilities for the Mentally Retarded: Their Position in the Continuum of Care for Developmentally Disabled and Mentally Retarded Individuals." Before responding to the facts and recommendations contained in your report relative to the seven residential facilities which are providing services to developmentally disabled individuals under the age of 21, I want to clarify the role that the State Education Department has had with these facilities.

In order for handicapped children under the age of 21 to access private residential facilities licensed by the New York State Office of Mental Retardation and Developmental Disabilities, it has been necessary for the State Education Department to approve these facilities in accordance with Chapter 853 of the Laws of 1976 as amended. This "853" approval permits public school districts to contract with these private residential facilities in those instances where the Committee on the Handicapped has recommended and the Board of Education has approved such placements. Based on a 1977 agreement with the New York State Office of Mental Retardation and Developmental Disabilities, the State Education Department's primary role with the private residential schools licensed by OMR/DD has been to ensure that the special education program and services provided to handicapped children meet the standards established by Federal and State laws and regulations. Consequently, while the Department's program review reports have addressed such issues as the living environments of the residents, incident review procedures and medical services, we have as a matter of practice relied on the New York State Office of Mental Retardation and Developmental Disabilities to enforce their regulations and laws relative to these areas. This practice is based in part on OMR/DD's statutory authority to enforce such standards as well as an acknowledgment that staff from the New York State Office of Mental Retardation and Developmental Disabilities possess an expertise regarding these areas that is unavailable within the State Education Department.

In light of the above, please allow me now to respond to those sections of the draft report that relate specifically to those private residential facilities licensed by the New York State Office of Mental Retardation and Developmental Disabilities and approved by the State Education Department as Chapter 853 schools. My response will follow the format contained in the draft report.

Programming

The positive comments contained in your report regarding the programming available at the Upstate Home for Children, the Cobb Memorial School, Margaret Chapman School and Rhinebeck Country School are consistent with observations made by Department staff during regularly scheduled program review visits. Also, I was pleased to see that your staff's review of randomly selected individual education programs was complete and written in behavioral terms incorporating both annual and short-term goals and instructional objectives.

Program Concerns

Cobb Memorial School - Page nine of the draft report indicates "the lack of vocational training available to female students who remain until they are age 21." This program area will be reviewed during the upcoming State Education Department's program review. I will have my staff provide you with a copy of the final program review report when it is available.

Arlene Training Center - The Department's June 1981 program review report reflected similar concerns regarding active programming, especially during the evening and weekend hours. While the school has corrected the compliance issues identified in our June 1981 report, the Department will, nevertheless, continue to work with the school on improving the program issues that we have mutually identified.

Environment

The State Education Department is also concerned about the kind of environments within which special education programming occurs for handicapped children. In this regard, the Department's program review reports contain a particular component that describes the physical environment as well as fire safety issues, accessibility and overall cleanliness. Consequently, I was pleased to read that the Rhinebeck Country School, Cobb Memorial School and Upstate Home for Children are providing an environment that is conducive to living and learning. Your findings concur with our observations at these schools.

Environment Concerns

Margaret Chapman School - Since developmentally disabled residents under the age of 21 live only in Sherman Hall, I will limit my comments to that particular aspect of residential programming at Margaret Chapman School. In April of 1981, State Education Department staff conducted a program review at the Margaret Chapman School. Our report raised specific

concerns regarding the physical deficiencies within the Sherman Hall residence. Subsequent to that report, the Margaret Chapman School provided the Department with a building maintenance plan. A follow-up visit to the school in the fall of 1981 was made to review the status of the program and compliance issues identified in our April report. At that time, the Sherman Hall residence was revisited by Department staff who noted several improvements within the dorm, such as repainting of bedrooms and corridors, new curtains, etc. Additionally, the school administration indicated, as early as the April 1981 program review visit, that a renovation plan was being submitted to the New York State Office of Mental Retardation and Developmental Disabilities. It is recommended that the Commission pursue the approval status of the renovation plan prior to issuing the final report.

Crystal Run School (Middletown Campus) - I was pleased to read that the Middletown Campus has added a semi-independent dorm to the campus. This should provide an opportunity for the program to increase community living skills for residents placed by Committees on the Handicapped who are aging out of the education system.

Administrative Concerns

As you know, the incident review process, provision of medical services and the provision of nursing services and first-aid training are requirements mandated under various sections of the Mental Hygiene Law and pertinent regulations administered by the New York State Office of Mental Retardation and Developmental Disabilities. Consequently, it would not be appropriate for me to respond to these issues.

Monitoring the Schools - The Focus of Many Efforts

The Department is aware of the problems that your draft report describes relative to monitoring private residential schools by various State agencies. In an effort to improve interagency communication regarding specific programmatic and fiscal issues relative to the private residential schools for the mentally retarded, the State Education Department has been involved in the following interagency activities:

-- Fiscal staff from the Department's Office for the Education of Children with Handicapping Conditions (OECHC) meet regularly with fiscal staff from the New York State Department of Social Services to discuss rate-setting methodologies, financial and auditing responsibilities and fiscal issues related to individual schools, etc.

-- Program staff from the OECHC meet regularly with staff in the Private School Unit of OMR/DD to discuss programmatic issues, the provision of technical assistance, etc.

-- Program staff from both SED and OMR/DD have made joint visits to several schools to determine how different regulatory requirements may be met within the framework of an existing program.

— Staff from OECHC will be meeting shortly with staff from the Private School Unit of OMR/DD to discuss a joint monitoring instrument that will incorporate the regulatory requirements of both agencies into a single monitoring tool.

These activities should help to alleviate some of the problems associated with the monitoring of private residential schools for the mentally retarded and developmentally disabled by several State agencies.

I trust the above comments address the issues raised in your draft report relative to those private residential schools serving residents under the age of 21 that are approved by the State Education Department as Chapter 853 schools.

Again, thank you for the opportunity to respond to this draft report. I look forward to receiving a copy of the final report when it is available.

Sincerely,

Gordon M. Ambach

Mr. Clarence J. Sundram, Chairman
New York State Commission on Quality
of Care for the Mentally Disabled
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Albany, New York 12210

New York State Coalition of Private Residential Facilities
for
Mentally Retarded/Developmentally Disabled Adults

October 29, 2982

Clarence J. Sundram, Chairman
New York State Commission on
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99 Washington Avenue
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Re: Commission Report on Private Residential Facilities

Dear Mr. Sundram:

I am writing to provide you with the comments of the Coalition of Private Residential Facilities for the Mentally Retarded/Developmentally Disabled Adults on the confidential draft of the Commission's report entitled "A Review of Private Residential Facilities for the Mentally Retarded: Their Position in the Continuum of Care for Developmentally Disabled and Mentally Retarded Individuals".

At the outset, let me state that the Coalition members appreciate the opportunity to review and make comment upon the report prior to it's release. Additionally, the Coalition members very much appreciate the quality of work generally reflected in the draft. Overall, the report provides a substantially fair assessment of the strengths, weaknesses and needs of the private residential facilities.

The Coalition would like to direct its comments to the conclusions and recommendations made with respect to the facilities generally, as contained in pages 54-57 of the draft.

1) With respect to the first recommendation on the development of a single, multi-departmental set of regulations, you are aware of the Coalition's support of the Task Force previously created for regulatory revision. That Task Force was comprised of representatives from several State agencies as well as providers and parents. Unfortunately, despite the Coalition's repeated urgings to the contrary, the Task Force ceased meeting before its work ever seriously got underway.

Route 52, P. O. Box X, Loch Sheldrake, New York 12759

New York State Coalition of Private Residential Facilities
for
Mentally Retarded/Developmentally Disabled Adults

Clarence J. Sundram October 29, 1982

The need for some type of regulatory revision remains, as does the need for increase coordination and consistency among the agencies with oversight responsibilities vis-a-vis the private residential facilities. Accordingly, the Coalition strongly supports implementation of the Commission's first recommendation to this effect as contained in the draft report, with three additional considerations.

First, any task force or other group assigned the responsibility to review and revise the regulations should include among its members several service providers. Such inclusion can only enhance the ability to develop realistic regulations which can be met and adhered to by all providers.

Second, there is a need for two distinct sets of multi-departmental regulations, one applicable to children and one to adults. Obviously, each must mesh with the other, given the existence of facilities with both children and adult residents.

Third, and perhaps most importantly, the Coalition strongly supports the concept of diversity among private residential facilities - diversity as to philosophy, purposes, environment and client population. The regulators of the private residential facilities have historically pursued a limited service model which fails to encourage the development of different settings for MR/DD residents. It is the Coalition's position that this is a mistake, and that State policy should recognize, allow for and even encourage creative alternatives in the provision of services to the MR/DD adults. It is the Coalition's view that revision of the regulations applicable to the private residential facilities must be done in such a manner as to allow for differences in the delivery of services and diversity among providers, both now and into the future.

2) As to the second recommendation on conditional and corrective actions, the Coalition supports the suggestion that reasonable time limits be set for correction of major deficiencies, with certification to be revoked if corrections are not implemented. However, there must be some recognition and accounting for the direct link between corrective actions and the availability of sufficient funds to undertake such actions.

Route 52, P. O. Box X, Loch Sheldrake, New York 12759

Clarence J. Sundram October 29, 1982

3) The Coalition could not reach a conclusion with respect to the wisdom of pursuing the third recommendation on using the County Service Groups as technical advisors. The experience of Coalition members with the local County Service Groups varies greatly. In some cases, the interaction is very positive, in other cases, not particularly helpful. All agree that enhanced availability of technical assistance would certainly be welcome. There is also agreement on the need for clarification of the roles and division of responsibility between the Private School Unit and the County Service Groups.

4) With respect to the recommendation that a needs assessment be undertaken, there is no objection to such an assessment. The Coalition members do want to point out that they are faced with waiting lists and are currently unable to meet admission requests. The Coalition is deeply concerned over the lack of available residential alternatives. Existing state policy regarding development of more residential placement space is inadequate. Inappropriate placements and long waiting lists are the result.

5) The fifth recommendation on weighting critical compliance issues is supported by the Coalition. The Coalition has repeatedly requested that there be a more consistent process for determining "substantial compliance". There is also a continuing need for identifying the relative significance of various compliance issues.

These are the Coalition's comments with regard to the draft's conclusions and recommendations. One additional subject needs to be addressed, and that is the question of funding in Chapter 720.

The issue of supplemental funding in Chapter 720 monies is raised in the draft report in the context of "substantial compliance", or lack thereof. Several very important points need to be made if a complete picture is to be presented.

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New York State Coalition of Private Residential Facilities
for
Mentally Retarded/Developmentally Disabled Adults

Clarence J. Sundram

October 29, 1982

First, the level of funding provided private residential facilities under Chapter 720 is insignificant when compared to other service/provider modalities. Specifically, under Chapter 720, a private residential facility can receive approximately $13,000 per client per year, with $9,600 being closer to the norm. This contrasts with a range of $22,000 to $45,000 per year for children under 21 in in-state facilities funded through State Education Department. Community residences average expenditures of $28,600 per client per year, without including the cost of day treatment. The client cost per year at State ICFS and developmental centers averages approximately $43,200, again exclusive of day programming.

Many of the issues raised in the report on quality of life, particularly environment, directly relate to the insignificant and inadequate level of funding under Chapter 720. The private residential facilities should be analyzed, and criticized, within these budget cost constraints. The same, of course, is true of any recommendations for change and improvement. The Coalition welcomes improvement, but it can only come if there is adequate financing. Chapter 720 does not currently provide sufficient financing.

The authorizing legislation for Chapter 720 is due to expire in March of 1983. The Coalition will be seeking a continuation of the supplemental funding program as well as an increase in the funding level. Your support of this effort will be greatly appreciated.

Finally, as a last point on the issue of funding, we suggest that a report which focuses on the level of spending and the services provided for that level of spending for all types of providers be undertaken. This activity is within the Commission's legislative mandate to study cost effectiveness and would be very helpful as a tool for future policymaking.

Again, thank you very much for the opportunity to comment on the draft report. We look forward to your responses.

Very truly yours,

Daniel Berkowicz, A.C.S.W.
Ad Hoc Chairman

DB/lsh

cc: Members of the NYSCPRFMRDDA

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