PINELAND CONSENT DECREE

TABLE OF CONTENTS

Vol. 1

1. Brief of Wouri v. Zitany : Consent Judgement
Defendant's Objections to Part 1 of the Master's Report
Appendix "A" Pineland Center Standards
Appendix "B" Community Standards

2. Pineland Consent Decree: Report of the Special Master To the United States District Court for the District of Maine. March 19, 1979.

3. Pineland Consent Decree: Report of the Special Master... Part I: Conclusions of the Special Master. November 14, 1979.

4. Pineland Consent Decree: Report of the Special Master... Part II: Pineland Center November 14, 1979.

5. Pineland Consent Decree: Findings and Recommendations of the Special Master. MEDICAID: ICF-MR. December 24, 1979.

6. Wuori v. Zitany : Report of the Special Master COMMUNITY STANDARDS: APPENDIX B OF THE COURT'S DECREE April 22, 1980.

Vol. 2

1. Wuori v. Zitany: Findings and Recommendations of the Special Master: CONTINUING SUPERVISION OF THE DECREE June 2, 1980

2. Wuori v. Zitany: Report of the Special Master to the U.S. District Court. COMMUNITY PLACEMENT FOR PINELAND RESIDENTS. November 24, 1980.

3. The Martti Wuori Case Report to the Court. "How Maine Cares for its Retarded Citizens" July 20, 1981

4. The Martti Wuori Case-Report to the Court: "Maine's Mentally Retarded are Going Home" January 15, 1982.

5. The Martti Wuori Case-Report to the Court: "Maine's Communities and the Mentally Retarded. "Much Progress but more Remains." " July, 1982

6. Report to the Court on the Martti Wuori Case. "All Systems are go" October, 1983

MARTTI WUORI, et al.,

Plaintiffs

v.

GEORGE A. ZITNAY, et al.,

Defendants

---

Civil no. 75-80-SD

---

# FINDINGS AND RECOMMENDATIONS OF THE SPECIAL MASTER

---

CONTINUING SUPERVISION OF THE DECREE

---

June 2, 1980

TABLE OF CONTENTS


| | | |
|---|---|---|
| I. | THE PARTIES' CONSENT | 1 |
| II. | THE STATE OF COMPLIANCE | 5 |
| III. | FINDINGS OF FACT AND RECOMMENDATIONS | 13 |
| IV. | CONCLUSION | 16 |
| | APPENDIX: PROMISES MADE BY THE STATE TO THE PLAINTIFFS AND THE COURT | 17 |
| | CERTIFICATE OF SERVICE | 21 |

MARTTI WUORI, et al.,

Plaintiffs

v.

GEORGE A. ZITNAY, et al.,

Defendants

---

Civil no. 75-80-SD

---

FINDINGS AND RECOMMENDATIONS

OF THE SPECIAL MASTER

---

CONTINUING SUPERVISION OF THE DECREE

---

## I. THE PARTIES' CONSENT

These recommendations are rooted in the parties' consent. I recommend that this Court retain continuing jurisdiction over this cause for an additional two-year period and that the office of the Special Master be continued for a like term. Both of these actions were contemplated by the parties at the time of the entry of this Court's decree with the parties' consent. The parties agreed in advance to the Court's giving consideration to both of these actions.

The Court's decree was entered with the consent of the parties on July 14, 1978. With that act the implementation and enforcement phase of this litigation commenced. The Court took two actions to ensure that the Court's decree would be faithfully carried out. First, with the consent of the parties, the Court retained continuing jurisdiction of this cause. Second, by separate order

dated July 21, 1978, which was agreed to by the parties, the Court appointed a Master to oversee implementation of the Court's decree. Both actions were taken by the Court with the parties' consent. Both actions contemplated, by consent of the parties, consideration of renewal by the Court. As to retention of jurisdiction, this Court said: "The Court hereby retains jurisdiction over this matter for two years, at which time the Court shall consider whether to retain jurisdiction for an additional period of time." Wuori v. Zitnay, civil no. 75-80-SD, "Consent Judgment," para. 11 (July 14, 1978). As to appointment of a Master, the Court said: "The Court has determined that a Master should be appointed to monitor implementation of this decree." Id. at para. 10. "The Master shall act as an officer of the Court and shall serve solely the Court and the interests of justice. . . . The Master shall . . . serve for two years from the date of appointment, unless such term shall be extended by the Court." Wuori v. Zitnay, civil no. 75-80-SD, "Appointment of a Master," paras. 2-3 (July 21, 1978). The language suggesting reconsideration has an element of obligation: "the Court shall consider whether to retain jurisdiction for an additional period." The issue presented by the present recommendations is whether the Court has sufficient cause to relinquish retained jurisdiction and its oversight of the decree through the office of the Special Master.*

The procedure by which these recommendations come before the Court is the procedure to which the parties gave their consent. That procedure is set out in paragraph 6j of the order of July 21, 1978:

> (1) The Master shall have the authority to make recommendations with regard to implementation of the decree if: (a) he determines defendants are not in compliance with the decree; (b) this determination is accompanied by written findings of fact which indicate the source of the evidence upon which each finding is based; and (c) the recommendations are consistent with

---

*These recommendations do not touch upon the question of who should be selected as Special Master. That is a question which should be left in the first instance to the parties and, in the event that a Master cannot be selected by the parties' mutual consent, then to the Court. The Court has, in any event, retained the power to "appoint a replacement after consultation with the parties" "upon the resignation, termination for cause or inability of the Master to continue to serve." Order of July 21, 1978, "Appointment of a Master," para. 4.

and can be implemented within the framework of the decree. Such recommendations shall include, where necessary, timetables for implementation of steps or measures necessary to bring defendants into compliance.

(2) Copies of each recommendation accompanied by the findings of fact required by (1) of this paragraph shall be filed with the Court and served upon counsel for the parties. All parties shall be bound by the recommendation unless within 15 business days any party files an objection with the Master and requests a hearing. A copy of any such request shall be filed with the Court and served upon counsel for all parties. Objections may be made on the basis that (a) the findings of fact relied upon by the Master are erroneous, (b) the Master's determination of noncompliance is erroneous, or (c) the Master's recommendations are beyond the provisions of or inconsistent with the decree.

(3) The hearing on the objection shall be held before the Master at the earliest convenient time. Each party shall have the right to present evidence of a documentary and testamentary nature, and to cross-examine adverse witnesses. The Master shall make a record of all proceedings and render a written decision within 10 business days and provide the parties and the Court with a copy of the decision.

(4) The parties may agree prior to the hearing to be bound by the Master's written decision.

(5) If an agreement to be bound by the Master's decision has not been reached, any party may apply to the Court, with notice to all parties and the Master, for review of the Master's decision. An application for review must be filed within 15 business days after the Master's written decision is rendered. Upon receipt of the notice of application for review, the Master shall certify the record of hearing to the Court. Review shall be on the record unless the Court determines that a hearing is necessary. The Court may adopt the Master's decision or may reject it in whole or in part or may remand it with instructions.

The foregoing provisions embody part of the structure, agreed to by the parties, for ensuring that the State defendants comply with the consent decree. That structure imposes on the Special Master the duty to make recommendations with regard to implementation of the decree upon a determination that the defendants are not in compliance. A determination of noncompliance is presently inescapable. Thus, by agreement of the parties, the Master must now exercise the authority delegated to him to make an initial judgment on the steps required to ensure implementation of this Court's decree.

The consent decree is by its nature complex and on-going. The recommendation process, established by the Court and agreed to by the parties, is a mechanism for flexible yet orderly and effective implementation of the decree. The present recommendations are especially proper for presentation to the Court inasmuch as they carry forward judicial actions to which the parties gave their consent, which included consent to the Court's consideration of renewal, while the business of compliance remains incomplete. Given the facts that the parties consented to these actions in the first instance and consented in advance to the Court's consideration of their renewal, these recommendations are consistent with the decree and within its provisions.

## II. THE STATE OF COMPLIANCE

The present state of compliance with the Court's decree has been fully documented in reports submitted to the Court by the Special Master. The Special Master has filed three major reports with the Court, dated March 19, 1979, November 14, 1979, and April 22, 1980. The first report answered questions which had arisen frequently regarding the implications of a federal court injunction and contained an analysis of the principal objectives derivable from the Court's decree and an initial assessment of the state of compliance. The report of November 14, 1979, filed in two parts, sets out a comprehensive assessment of compliance with appendix A pertaining to Pineland Center. The report of April 22, 1980, closely analyzed 455 individual prescriptive program plans for community clients to determine the extent of compliance with appendix B, community standards. These reports contain the findings of the Master and make explicit reference to the evidence upon which these findings are based. Virtually all of the evidence of the State's failure to comply with the Court's decree comes from the State itself. In addition to the reports filed with the Court, the Master has made one set of formal findings of fact and recommendations, pertaining to the establishment of a system of intermediate care facilities for the mentally retarded under the federal medicaid program. (The recommendation would require shifting administrative responsibility of the ICF-MR component of the medicaid program from the Department of Human Services to the Bureau of Mental Retardation, a division of the Department of Mental Health and Corrections. The State responded by proposing to establish an ICF-MR system through a joint, cooperative effort of the two departments. The Master's recommendations are now being held in abeyance, essentially being continued on a month-to-month basis, by the consent of the parties while the parties and the Master observe the State's performance pursuant to its counter-proposal. Whether the Master can withdraw his recommendation depends entirely upon the quality of the State's product which is at this point in doubt.*)

---

*At the March meeting of counsel and state-agency representatives the State presented its proposed regulations to govern homes to be designated as intermediate care facilities for the mentally retarded. The proposed regulations were largely identical to the State's current boarding home regulations (which are contrary to both the terms and purposes of the Court's decree) with additions from the consent decree and federal ICF-MR regulations. Based on the consent decree, plaintiffs' counsel and the Master made detailed, page-by-page objections and general objections to the philosophy of the proposed regulations. At the April meeting the State tendered essentially the same regulations with some tinkering. At this point the State's proposed regulations were rejected by the Master, and the State was

(footnote continued on next page)

The Court's decree is a major structural injunction. It calls for thorough-going reform of Maine's principal institution for persons who are mentally retarded. It establishes their rights as long as they are confined to the institution; it establishes their right to leave the institution; and it establishes their right to be provided with more normal arrangements to live, learn, and work in the community. Most decree provisions carried a deadline of July 14, 1979. All decree provisions carry an ultimate deadline of July 14, 1980.

The consent decree is notable for its comprehensiveness and specificity. The decree leaves little room for argument on its meaning; it is free from significant ambiguity. While the decree may be ambitious, its standards are sound. The timelines in the decree (which were consented to by the State) were "realistic" in the sense that one could have reasonably expected the State to meet the obligations which the State promised to fulfill well within

---

(footnote continued from previous page)

given the options of adopting the federal ICF-MR regulations or the consent decree or having the Master undertake to cure the State's default by preparing regulations consistent with the decree and relevant federal law. It was agreed that the Master should write proposed regulations. The Master's office, in cooperation with the Bureau of Mental Retardation, prepared regulations which are consistent with the decree and federal ICF-MR regulations and satisfactory to the Bureau of Mental Retardation. At the May meeting of counsel the Department of Human Services presented its regulations, which had again been tinkered with, and represented that the Department would not and could not license homes under the Master's proposed regulations. The only objections to the Master's proposed regulations were (1) they would require changing the forms used to license community facilities and (2) they were not in the same sequence as the federal regulations. (They were in fact organized and written so that a person of ordinary intelligence could understand them and a group home established pursuant to the Court's decree could comply with them at reasonable cost and without requiring unnecessary expenditures.) At the present time it appears that the State's final position will have to be decided at the commissioner level or at the level of the Ad Hoc Panel on the Consent Decree, which was established by the Governor's office in response to the Master's medicaid recommendations.

the deadlines established. The State has represented to the Court that the Master "has acknowledged that the time frames in the decree are unrealistic." On the contrary, the time frames are "realistic." But, by the time the Master had observed the State's performance for the better part of a year, it was clear that the State would not and could not meet the decree's deadlines given its approach to compliance.

At the time the decree was entered there was every reason for an outsider, one unfamiliar with the normal processes of state government, to believe that the decree would be fully implemented by July 14, 1980. The Pineland consent decree had all the components of success. Unlike the ordinary structural injunction, the Court's entry of the decree in this case did not follow an extended period of acrimonious litigation. The decree was consented to by the State upon the personal approval of the then-Governor and then-Attorney General. The persons who participated in writing the decree were the same ones who had the major responsibility for carrying it out. They knew the decree intimately after having negotiated it line by line. They were philosophically committed to the decree. In July 1978 the Special Master fully expected that the decree would be implemented -- that the State would have fully complied with the law which it wrote and promised to carry out -- by July 14, 1980.*

---

*Upon being appointed, the Master undertook, as the first order of business, a three-day tour of Pineland Center. During that tour, the superintendent of Pineland constantly pointed out, in the presence of another state officer, places at Pineland and areas of the decree as to which the State would have to "go back to Judge Gignoux" or "obtain an exception" from the decree. It thus appears that, within two weeks of signing the consent decree, the state official in charge of the institution knew that the State would not comply with its terms and expected that they could be relieved from the obligations they had so recently voluntarily assumed. The State has told the Court that "[i]n some instances defendants will not meet the time frames set forth in the decree," and the State defends its failure on the ground that those timelines are "unrealistic." See Defendants' Objections to the Master's Report, p.7 (Jan. 1980). I know of no evidence that the superintendent's views were shared by the other state signatories to the Court's decree; in fact, all evidence of which I am aware is to the contrary. I believe, however, that they entertained an expectation of cooperation by state officials and agencies not named as defendants, which was not forthcoming and which is now being only partially and occasionally extended.

It cannot be gainsaid that implementation of the Court's decree is an administratively complex undertaking. The institution alone has 384 residents, virtually all of whom are involuntarily confined, and 784 employees not counting others who work there as volunteers or as independent contractors. Aside from the institution, the Bureau of Mental Retardation has six regional offices and two resource centers. The Bureau has 223 employees serving approximately 1931 clients of whom 564 are members of the plaintiff class. Community residences, day programs, and many services are not provided directly by the State but rather by hundreds of private individuals, corporations, and associations under contract with the State. Implementation of the decree depends in large part on the cooperation of coordinate state agencies, the officers of which are not named defendants in this lawsuit, including the Maine Departments of Human Services, Educational and Cultural Services, Personnel, Finance and Administration, and Transportation.

Speedy compliance with a federal court order of the magnitude of the Pineland consent decree cannot be achieved if the business of state government is conducted as usual. Entry of the decree is an extraordinary event requiring an extraordinary response. The decree reverses basic tenets of the State's treatment of mentally retarded citizens. It promises normal living, specially designed educational and occupational opportunities, new support services. The State has not responded nearly as well to its decree obligations as it could have. The decree has been subjected to the normal processes of state government instead of those processes' responding to the decree. Administrative complexity of compliance is not a reason for condoning the State's failure to do what it promised to do; it is a reason for the Court's continuing its supervision of its decree. Patience is definitely required but patience accompanied by the Court's vigilance and continued assistance to the named defendants.

The standard by which the Court should be governed in determining whether to relinquish continuing jurisdiction is whether the State is in compliance with the Court's order or in such substantial compliance that full implementation of the decree is assured. The standard by which the Court should decide whether to permit expiration of the Master's office is whether the engines of compliance are sufficiently in place that, barring unforeseeable and unlikely obstructions, they will suffice to carry out the decree's requirements. Neither of these standards is met.*

---

* The recommended term of continuing supervision, two years, is simply a renewal of the period to which the parties gave their consent. While there is reason for recommending a longer term, there is no basis for recommending a shorter one.

The report of April 22, 1980, shows that sixty per cent of the members of the plaintiff class who have been discharged from Pineland live in places which do not comply with the environmental and programmatic standards of the decree. (This number does not include persons who, while residing in good homes which meet decree standards, are ready to live in a less restrictive setting such as supervised, semi-independent living arrangements but cannot do so because of the State's failure to provide a full range of less restrictive alternatives.) Fifteen per cent of the class members have no program activity at all, and a probable majority have programmatic opportunities unsuited to their needs. Family-support and crisis-intervention services are virtually nonexistent; advocacy and other professional services are inadequate.

The report of November 14, 1979, shows that most living arrangements at Pineland Center do not conform to the Court's decree. Pineland residents are not being accorded the individually planned program activities to which the decree entitles them. Staff ratios are not now and never have been met. Pineland residents are not being adequately prepared to leave the institution. Part I of that report raised the question of whether Pineland Center could ever be expected to comply with the court order. I am not advocating that Pineland Center be closed. As matters now stand, the State is essentially confronted with the option of choosing among three imperatives: Dramatically increase expenditures at Pineland Center for increased staff, renovations, and staff training.* Give the Superintendent control over his own budget and personnel in the hope that he can, without greater expenditures, bring about significant improvements. Phase out the institution as a place for long-term confinement by continued periodic reductions in the resident population.**

---

* The cost of operating Pineland Center last year was approximately $30,000 per resident. The total cost of operating Pineland Center last year was approximately $12,000,000. Decree requirements are not being met at this price. In part I of my report dated November 14, 1979, I stated that I would not recommend that the Court require the State to choose this option to spend additional millions at Pineland Center.

** Pineland Center was without a superintendent from October 1978 to October 1979. For several months Pineland Center has been in the process of reorganizing. Massive relocations of Pineland residents have occurred. Changes in employees' working hours and assigned duties have been made. This reorganization was not effected through the decree mechanisms established for individual planning. The reorganization is not designed itself to bring Pineland Center into compliance with the decree. Rather, it is designed to provide a foundation for commencing to comply with the decree. Recognizing that the reorganization of Pineland would, in effect, amount to a suspension of the decree, the Master invited Pineland Center to submit
(footnote continued on next page)

In my judgment, the key and principal engine of compliance is what the State terms "resource development," i.e., the State's activity in causing to be established new community-based homes, programs, and support services for retarded citizens.* Increased development of such resources would enable providing each member of the class with the kind of home and educational or occupational opportunity to which he is entitled, would release the State from its dependency on home operators who are unwilling or unable to carry out the decree, and would facilitate improvements at Pineland by reducing the number of persons who are confined there. One means by which resource development can be improved is by taking proper advantage of that aspect of the federal medicaid program known under the designation of intermediate care facilities for the mentally retarded. Others include such federal programs as special education for the handicapped, vocational rehabilitation, vocational education, title XX of the Social Security Act, and federal programs relating to transportation and housing. A second engine of compliance is the establishment of continuing monitoring systems through the decree-based Consumer Advisory Board, the advocates, and state licensing and inspecting agencies. Recommendations on these subjects are currently being prepared by the office of the Special Master.**

---

(footnote continued from previous page)

its plans for reorganization to the Court for the Court's approval. This procedure would have had the effect of giving legitimacy to what amounts to the State's suspension of the decree. The State did not take advantage of this opportunity. We cannot now say whether the Pineland reorganization will provide a foundation for complying with the decree or whether it is simply an institutional response to criticism which will have few positive results. Massive reorganizations have taken place at Pineland in the past without yielding beneficial results.

* A new component of resource development must also be added. The State must establish a sound educational program for educating persons to become teachers and helpers for the mentally retarded.

** The Special Master is also involved in several other matters of current business. First, we will soon know of the adequacy of the State's response to the Master's recommendations on establishing a system of intermediate care facilities for the mentally retarded. If the State's response is inadequate, hearings will have to be commenced looking ultimately to an appeal to this Court. Second, the Maine Superior Court has sustained a determination by a local zoning board that a group home for retarded citizens
(footnote continued on next page)

A high degree of cooperation among a variety of state officials and agencies is necessary to allowing these engines to run their course once they are in place. Improvements in securing such cooperation have been made, due largely to the Court's retention of jurisdiction and the efforts of the Special Master. But the failure of cooperation is still the major obstruction of the Court's decree. The problem of noncompliance is not essentially financial.*

---

(footnote continued from previous page)

cannot be located in a zone for single-family homes. See Penobscot Area Housing Development Corp. v. Weatherbee, docket no. 79-484 (Super. Ct., April 16, 1980). The Special Master has sought the consent of all parties, pursuant to rule 75A(f) of the Maine Rules of Civil Procedure, to appear as amicus curiae in the appeal to the Supreme Judicial Court of Maine. The Master would participate for the purpose of providing the Law Court with a discussion, from the perspective of federalism, of the relevance of this Court's order to the issues presented on appeal. Third, an arbitrator has decided that a collective-bargaining agreement prevails over this Court's decree in a case alleging physical abuse of a Pineland resident by a state employee. See In re Maine and Council 74, AFSCME, John E. Sands, arbitrator (tent. award, May 9, 1980). The Master has fully informed the parties of his analysis of the issues and is awaiting their comments and advice.

* One of the highest priorities of the Special Master and a demand made upon the State by the Special Master was to certify Pineland Center as an intermediate care facility for the mentally retarded. This measure has now been accomplished, and, if it has been done properly, between six and seven million dollars in federal assistance is now flowing into the State's general fund annually. This money is being collected by the State on the account of mentally retarded citizens who are involuntarily confined to Pineland and whose rights under this Court's decree are being denied. Its receipt by the State is attributable in large part to the Court's decree and the decree's enforcement authority. In these circumstances, it would be wholly appropriate for the State to treat these funds as received in a fiduciary capacity and to devote them exclusively to compliance with the decree of this Court. If the funds were devoted to resource development without replacing current State appropriations, financing of resource development would be adequate in the long run to the task of complying with the order of the Court.

Obstruction of the decree is not essentially a question of attitude among persons who work with retarded individuals or among Maine citizens in general.* The problem of noncompliance (aside from problems inherent in an institution) is a matter of administrative law.** State administrative law more than anything else accounts for the disparity between the promise embodied in the Court's decree and the actual lives of the members of the plaintiff-class.

Because of the administrative complexity of compliance the State has asserted that it needs more time to comply. The State failed to reach substantial compliance during this Court's supervision over its decree. There is no basis for presuming that the State will attain compliance or substantial compliance without the Court's continuing supervision.

---

* To the extent that a general attitude adversely affects compliance, it can be readily addressed by a program of public education implemented by the State.

** See, e.g., footnote, pages 5-6, supra.

## III. FINDINGS OF FACT AND RECOMMENDATIONS

A. Determination of Noncompliance.

The defendants are not in compliance with the Court's decree. This determination is based on the following findings of fact.

B. Findings of Fact.

1. Residents of Pineland Center are not being provided with their minimum entitlement to individually planned programs of habilitation and are not being allowed to live and learn under conditions conforming to the decree's standards of normalcy and in the least restrictive conditions necessary to achieve the purposes of habilitation.

> [This finding is based on Pineland Center's official programming statistics, an examination of Pineland's interdisciplinary team reports, personal observation of programs and residences at Pineland Center, and interviews with Pineland residents.]

2. Pineland Center has an insufficient number of staff to meet minimum decree ratios, to provide safety and care to Pineland residents, and to fulfill the obligations imposed upon them by the State and the Court's decree.

> [This finding is based on records of Pineland Center's personnel and medical departments and an analysis of Pineland accident reports and personnel statistics prepared by the advocate for Pineland Center.]

3. Residents of Pineland Center are being confined to Pineland because the State has failed to provide suitable community residences, suitable programs in the community, and adequate support services including crisis-intervention and respite care.

> [This finding is based on records of Pineland Center's department of social services, interdisciplinary team reports, interviews with social services personnel, community resource developers, community service workers, and community service providers, and the records of the Maine District Court pertaining to certification of Pineland residents.]

4. Plaintiffs who are no longer confined to Pineland Center are living in places which substantially fail to conform to the purposes and terms of the Court's decree.

> [This finding is based on personal observation of community residences, interviews with community service workers, advocates, and former Pineland residents, an analysis of prescriptive program plans for community clients, and a survey of community-service workers.]

5. Plaintiffs who live in community homes are not being provided with programs suited to their needs or support services adequate to meet actual client needs.

> [This finding is based on interviews with community service workers, advocates, and former Pineland residents, an analysis of prescriptive program plans for community clients, and a survey of community service workers.]

6. Plaintiffs who could live with their own families or who could live under semi-independent conditions are being denied the right to do so by the State's failure to provide family-support services and by the State's failure to provide a full range of increasingly less restrictive living arrangements.

> [This finding is based on interviews with community service workers, advocates, attorneys for Bureau clients, resource developers, and community-service providers.]

7. The State does not know the extent to which it is failing to meet the plaintiffs' actual needs as to residence, program, or support services.

> [This finding is based upon an analysis of prescriptive program plans for community clients and interviews of central-office personnel of the Bureau of Mental Retardation.]

The foregoing findings of fact apply in each case to a substantial number of members of the plaintiff class. They are corroborated and documented in reports of the Special Master previously submitted to the Court. The Special Master believes that all of the foregoing findings of fact apply in each case to a substantial number of members of the plaintiff class. The Special Master believes that all of the foregoing findings can be established at an evidentiary hearing exclusively through the official records of agencies of this State and the testimony of employees of the State of Maine.

C. Recommendations.

1. The Court should renew its retention of jurisdiction over this matter for two years, at which time the Court should consider whether to retain jurisdiction for an additional period of time.

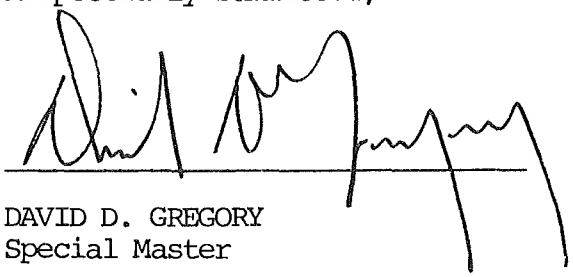
2. The Court should renew its appointment of a Special Master to serve for two years unless such term shall be extended by the Court.

3. In the event that proceedings for reaching a final determination on these recommendations have not concluded by July 14 and July 21, 1980, respectively, the Court should enter an interim order retaining jurisdiction and renewing its appointment of a Special Master until such time as proceedings have concluded.

## IV. CONCLUSION

The foregoing findings of fact and recommendations are submitted to the Court for the reasons explained herein pursuant to paragraph 6j(2) of the order of July 21, 1978, "Appointment of a Master."

Respectfully submitted,



DAVID D. GREGORY
Special Master

Dated: June 2, 1980
Portland, Maine

Professor David D. Gregory
University of Maine School of Law
246 Deering Avenue
Portland, Maine 04102

APPENDIX

PROMISES MADE BY THE STATE

TO THE PLAINTIFFS AND THE COURT:

SELECTED EXCERPTS FROM THE CONSENT DECREE

[Pineland residents] have a right to habilitation . . . suited to their needs, regardless of age, degree of retardation or handicapping condition. Each resident has a right to a habilitation program which will maximize his human abilities, enhance his ability to cope with his environment and create a reasonable expectation of progress toward the goal of independent community living. [Appendix A, § A.1.]

Residents shall be provided with the least restrictive and most normal living conditions possible. . . . Residents shall have a right to the least restrictive conditions necessary to achieve the purposes of habilitation. [Appendix A, §§ A.2,3.]

Defendants shall provide living facilities which afford residents privacy, dignity, comfort and sanitation. . . . Living, programming and working areas shall be quiet . . . . Every building shall be kept clean . . . . [Appendix A, §§ B.1, 6, 7.]

Living unit staff shall . . . develop and maintain a warm, home-like environment conducive to the habilitation of each resident and consistent with the normalization principle . . . . [Appendix A, § C.1.]

Each resident shall have an individual plan of care, development and services . . . . Each program plan shall describe the nature of the resident's specific needs and capabilities, his program goals, with short-range and long-range objectives and timetables for the attainment of these objectives. The prescriptive program plan shall address each resident's residential needs, medical needs, ADL skill learning needs, psychological needs, social needs, recreational needs, and other needs including educational, vocational, physical therapy, occupational therapy, and speech therapy, as appropriate. The individual program plan shall include a clear explanation of the daily program needs of the resident for the guidance of those responsible for daily care. The recommendations included in each resident's prescriptive program plan, both as to residential and programming placements, shall in all cases be the least restrictive placements suited to the resident's needs. The recommendations of the prescriptive program plan shall be based on the interdisciplinary team's evaluation of the actual needs of the resident rather than on what programs are currently available. . . . The prescriptive program plan shall provide . . . for at least six hours of program activity per weekday for each resident. Each resident shall receive these scheduled hours of programming. This program

activity shall be designed to contribute to the achievement of objectives established for each resident in his prescriptive program plan. . . . Pineland shall provide the programming recommended by the resident's prescriptive program plan within 30 days of the preparation of the plan. [Appendix A, §§ D.1, 4, 8, 11.]

The educational philosophy shall be that all residents are presumed to be capable of benefitting from education. . . . Educational services at Pineland shall, at a minimum, be equivalent to the special educational services provided in the community in accordance with Maine law . . . . Those residents with specialized needs, such as the blind, deaf and multiply handicapped, shall receive programs of special education and development specifically designed to meet those needs . . . . [Appendix A, §§ G.1, 2, 6.]

Consistent with their capabilities and handicaps, residents shall be taught to feed themselves and shall be fed both hot and cold foods and beverages in a normal fashion, in cheerful dining room surroundings . . . . Residents shall be provided with clean, adequate and seasonably appropriate clothing which is comparable in style and quality with clothing worn by persons of similar age and sex in the community. [Appendix A, § F.1, 10.]

[Living unit staff shall] develop and maintain a warm, home-like environment conducive to the habilitation of each resident and consistent with the normalization principle; . . . facilitate enjoyment by each resident of a "rhythm of life" consistent with the cultural norms for the resident's nonretarded peers . . . . [Appendix A, § C.1(a), (b).]

Individualized physical therapy services on a regular basis shall be provided to those residents who can benefit therefrom . . . . [Appendix A, § K.1]

No person shall be admitted to Pineland unless a prior determination is made that residence at Pineland is the least restrictive habilitation setting feasible for that person. No mentally retarded person shall be admitted to Pineland if services and programs in the community can afford adequate habilitation to such person. [Appendix A, § A.4.]

[A]ll steps, standards and procedures contained herein . . .shall be achieved, and thereafter maintained within 12 months of the signing of this decree. [Appendix A, § W.1.]

This decree shall be interpreted in a fair and reasonable manner so as to attain the object for which it was designed and the purpose to which it is applied. [Appendix A, § W.8.]

Clients have a right to habilitation, including medical treatment, education, training and care, suited to their needs, regardless of age, degree of retardation or handicapping condition. Each client has a right to a habilitation program which will maximize his human abilities, enhance his ability to cope with his environment and create a reasonable expectation of progress toward the goal of independent community living. . . . Each client shall be provided with the least restrictive and most normal living conditions appropriate for that client. . . . Clients shall be prepared to move from: (1) living and programming segregated from community to living and programming integrated with the community; (2) more structured living to less structured living; (3) larger living units to smaller living units; (4) group residences to individual residences; (5) dependent living to independent living, as appropriate for the individual client. [Appendix B, § F.1(a), (b), (c).]

Defendants shall ensure that community living facilities afford clients privacy, dignity, comfort, sanitation and a home-like environment. [Appendix B, § F.2(a).]

Each client shall have . . . an individual plan of care, development, and services . . . . Each program plan shall describe the nature of the client's specific needs and capabilities, his program goals, with short-range and long-range objectives and timetables for the attainment of these objectives. The prescriptive program plan shall address each client's residential needs, medical needs, ADL skill learning needs, psychological needs, social needs, recreational needs, transportation needs, and other needs including educational, vocational, physical therapy, occupational therapy, and speech therapy, as appropriate. The prescriptive program plan shall include a clear explanation of the daily program needs of the client for the guidance of those responsible for daily care. The recommendations included in each client's prescriptive program plan, both as to residential and programming placements, shall in all cases be the least restrictive placements suited to the client's needs. The recommendations of the prescriptive program plan shall be based on the interdisciplinary team's evaluation of the actual needs of the client rather than on what programs are currently available in the community. . . . [Appendix B, § B.1, 4.]

Each client's prescriptive program plan shall provide for a minimum of four scheduled hours of program activity per week day, and each client shall receive this programming. This program activity shall be designed to contribute to the achievement of objectives established for each client in his prescriptive program plan. . . . In addition to the four hours of programming required . . . , each client shall receive training in his residential setting in everyday living skills . . . . [Appendix B, § B.7(b), (c).]

Community facilities shall be integrated into the community. [Appendix B, § C.12.]

The defendants shall provide crisis intervention services in emergency situations which threaten a client's program or residential placement. Resource center staff with skills in crisis intervention and behavior programming shall provide intensive intervention at the community placement. Only if intervention at the community placement fails or if the crisis intervention team, after seeing the client, determines that immediate movement is necessary shall the client be moved to a respite care facility. . . . [Appendix B, § D.3.]

Respite care or temporary residential assistance shall be available to clients by December 1, 1978. When respite care is reasonably needed, it shall be provided in community facilities. Pineland may be used for respite care purposes of a specialized nature only. [Appendix B, § D.4(a).]

The defendants shall ensure that sufficient transportation is available so that clients can attend all recommended program activities and professional services, and so that recreation, shopping and other community activities are reasonably accessible to each client. . . . [Appendix B, § D.6.]

Defendants shall provide by October 1, 1978, a full range of support services for the families of all those clients living with their natural, adoptive or foster family. . . . All services available to residents of group homes or other community placements shall be available to clients living at home. . . . The Bureau shall assist in securing homemaker services to a client's family when needed to enable the family to adequately care for the client. . . . The Bureau shall make available training in caring for the retarded for sitters and homemakers. [Appendix B, § D.7.]

Unless otherwise specified, steps, standards and procedures contained herein shall be achieved, and thereafter maintained, within 12 months from the date of the signing of this decree. [Appendix B, § J.1.]

This decree shall be interpreted in a fair and reasonable manner so as to attain the object for which it was designed and the purpose to which it is applied. [Appendix B, § J.8.]

CERTIFICATE OF SERVICE

I hereby certify that the foregoing Findings and Recommendations of the Special Master were served upon counsel of record by hand-delivering this day one copy to the business offices of each of the following persons:

Honorable Richard S. Cohen
Attorney General
State House
Augusta, Maine 04333

William H. Laubenstein, III
Assistant Attorney General
State Office Building
Augusta, Maine 04333

Neville Woodruff
Helen Bailey
193 Middle Street
Portland, Maine 04101

and by depositing this day in the United States mail, postage prepaid, one copy addressed to each of the following persons:

Jane Bloom Yohalem
Robert Plotkin
Mental Health Law Project
1220 Nineteenth Street, N.W., Suite 300
Washington, D.C. 20036

Date June 2, 1980

Arthur R. Dingley

ARTHUR R. DINGLEY
Assistant to the Special Master

MARTTI WUORI, et al.,

Plaintiffs

v.

GEORGE A. ZITNAY, et al.,

Defendants

---

REPORT OF THE SPECIAL MASTER

TO THE UNITED STATES DISTRICT COURT

---

COMMUNITY PLACEMENT FOR PINELAND RESIDENTS

---

November 24, 1980

TABLE OF CONTENTS


| | | |
|---|---|---|
| I. | INTRODUCTION | 1 |
| II. | DECREE REQUIREMENTS | 3 |
| III. | ANALYSIS OF PLACEMENT RECOMMENDATIONS | 6 |
| | A. CHARACTERISTICS OF HOMES | 6 |
| | B. SPECIAL FEATURES OF NEEDED HOMES | 7 |
| | C. PROGRAMS | 8 |
| | D. LOCATION PREFERRED | 9 |
| | E. OBSTACLES TO PLACEMENT | 10 |
| | F. OBSERVATIONS ON ANALYSIS | 11 |
| IV. | CONCLUSION | 13 |
| | APPENDIX I: RECOMMENDATIONS FOR PLACEMENT | 14 |
| | APPENDIX II: RECOMMENDATIONS AGAINST PLACEMENT | 46 |

MARTTI WUORI, et al.,

Plaintiffs

v.

GEORGE A. ZITNAY, et al.,

Defendants

---

Civil no. 75-80-SD

---

REPORT OF THE SPECIAL MASTER

TO THE UNITED STATES DISTRICT COURT

FOR THE DISTRICT OF MAINE

---

# COMMUNITY PLACEMENT FOR PINELAND RESIDENTS

---

## I. INTRODUCTION

This report is the fourth in a series of semi-annual informational reports which the Master is required to file by order of the Court dated July 21, 1978 (which was extended by order of July 1, 1980). Earlier reports have been submitted to the Court on March 19, 1979 (discussing implications of the consent decree and stating preliminary observations on implementation), November 14, 1979, parts I and II (compliance at Pineland Center, appendix A), and April 22, 1980 (compliance with community standards, appendix B). The present report describes the bridge for Pineland Center residents between appendices A and B of the consent decree: the right guaranteed by the decree to move from the institution to the community.

We reported to the Court just one year ago that Pineland Center was denying the right of Pineland residents to noninstitutional living. See Report of the Special Master, Nov. 14, 1979, part I, at 2. Our findings then indicated that Pineland Center, so far from facilitating community

placements, was obstructing the right of Pineland residents to live in more normal, less restrictive community homes. See id., part II, at 138-46. The present report documents three notable changes. First, Pineland Center is now taking seriously the community-placement needs of Pineland residents. Second, the product of such serious consideration is that over ninety per cent of the residents of Pineland have been recommended by Pineland Center for community placement. Third, the barrier to placement is not Pineland Center but a severe lack of suitable, often specialized homes, programs, and support services in the community.

The information contained in this report is critical to assessing compliance with the decree because it goes straight to the decree's central objectives. The twin objectives derivable from the decree are to secure the right to live and learn in the least restrictive environment possible (measured by an individual's personal needs and capabilities) and to secure the right to education, training, and a productive occupation designated in the decree as "programming." The decree specifically provides that "[t]his decree shall be interpreted in a fair and reasonable manner so as to attain the object for which it was designed and the purpose to which it is applied." Appendix A, § W.8; Appendix B, § J.8. The Master's reports have thus consistently emphasized the central objectives of education and normalcy. See Reports of the Special Master, March 19, 1979, at 5; Nov. 14, 1979, part I, at 6, part II, at 1-3; id. passim; April 22, 1980, at 2-3. The present report is the most complete catalogue yet compiled of the homes, programs, and services which the State needs to provide in order to secure in fact the rights of Pineland residents which the State has consented to guarantee in law. This report, coupled with the report of April 22nd on the placement and programming needs of community clients, see id.at 65-66, 75-77, 41-47, provides a comprehensive guide to planning resource development and formulating budgetary requests sufficient to underwrite resource development.

Because of the obvious linkage between data on unmet client needs and planning for full compliance, the decree requires the State to compile continually the kind of information contained in this report. See Appendix B, § C.14; Appendix A, § D.4; Appendix B, § B.4. Yet this report by the Master's office is the first such compilation. (Even so, our access to the information reported here was not easily obtained.)

Finally, the State cannot tenably claim that it lacks the funds necessary for providing the new community homes, programs, and services described in this report. As a result of the efforts of the Special Master, the State is now qualifying for federal reimbursement for the cost of operating Pineland Center. See Findings and Recommendations of the Special Master, June 2, 1980, footnote at 11. The State now agrees with our projected estimate of nine million dollars available annually to the State. This money, which is received by the State on account of the residents of Pineland Center, could and should be used for their benefit to establish the new community homes and programs they need. Moreover, as a result of the Master's efforts, seventy percent of the cost of operating those community homes and programs would be paid by the federal government. See Findings and Recommendations of the Special Master, Dec. 24, 1979. The State is receiving sufficient federal funds to enable it to comply with the decree.

## II. DECREE REQUIREMENTS

One of the most important rights guaranteed by the consent decree is the right of Pineland residents to live outside the institution. This right is not measured by those alternative living arrangements which are currently available. Rather individuals possess a personal and present right to live in the least restrictive environment which can meet their own individual needs. The State's duty is to provide the alternatives.

> Each [Pineland] resident has a right to a habilitation program which will . . . create a reasonable expectation of progress toward the goal of independent community living . . . . [Pineland] [r]esidents shall have a right to the least restrictive conditions necessary to achieve the purposes of habilitation. To this end, Pineland shall make every attempt to move residents from (1) more to less structured living; (2) larger to smaller facilities; (3) larger to smaller living units; (4) group to individual residences; (5) segregated to integrated community living; (6) dependent to independent living. [Appendix A, §§A.1, A.3.]

The mechanism, established by the decree, by which this right is to be secured for each individual at Pineland is called the interdisciplinary team. The team includes professionals with expertise in a variety of disciplines and other persons who are most knowledgeable about individual plaintiffs. The team meets at least annually to assess an individual's needs and prepare an individual program plan to address those needs.

> Each [Pineland] resident shall have an individual plan of care, development and services. . . . [Appendix A, §D.1.]
>
> Each [Pineland] resident's prescriptive program plan shall include an analysis of the community placement best suited for that resident and a projected date for the resident's progress to a community setting. . . . [Appendix A, §A.5.]
>
> The prescriptive program plan shall address each resident's residential needs . . . . The recommendations included in each resident's prescriptive program plan, both as to residential and programming placements, shall in all cases be the least restrictive placements suited to the resident's needs. The recommendations of the prescriptive program plan shall be based on the interdisciplinary team's evaluation of the actual needs of the resident rather than on what programs are currently available. . . . [Appendix A, § D.4.]
>
> As part of the individual evaluation required by Appendix A, Section D of this decree, each resident's Pineland interdisciplinary team shall determine whether placement in the community is appropriate, and, if so, shall make a community placement recommendation. Community placement decisions

> shall be based on a determination that the placement will offer the individual a better opportunity for personal development and a more suitable living environment, and will result in placement in the least restrictive alternative appropriate for the resident. [Appendix B, §A.2.(a).]

These provisions describe how the right to community placement is to be secured for any given individual Pineland resident. It is an orderly, professional, and personal process. It prevents haphazard discharge from the institution. The interdisciplinary team answers the question of whether a person is capable of living outside the institutional setting and, if so, what services the State must provide to support him in a more normal environment. The decree then specifies the duty of the State with respect to implementing the recommendations made by the interdisciplinary team.

> Following a determination . . . that placement in the community is appropriate for a resident, a community service worker shall be assigned to that resident and the community service worker's name shall be recorded in the resident's file. The community service worker shall then locate and/or develop, in consultation with the resident and with the resident's correspondent (unless a competent resident objects to the correspondent's involvement), a community placement that is in conformance with the recommendations of the interdisciplinary team. [Appendix B, §A.2(b).]

> "Community placement" refers to a residence in the community in a group home, foster care home, natural home, apartment, boarding home, or similar residential facility coupled with a program element adequate to meet the client's individual needs. [Appendix B, definition 20.]

> In cases where the services needed by a resident are unavailable, the IDT shall so note in the prescriptive program plan and shall recommend an interim program based on available services which meet, as nearly as possible, the actual needs of the resident. The number of residents in need of a service which is not currently available and the type of program each needs shall be compiled and these figures shall be used to plan for the development of new services and programs. [Appendix A, §D.4.]

In sum, individual Pineland residents have a right to live and learn in the least restrictive environment suited to their needs. The State, by consenting to the decree, has voluntarily assumed the legal obligation to provide community homes, programs, and services to meet those needs. The reference above to the duty to "develop . . . a community placement" refers to the process of establishing new homes, programs, and services in the community. The State calls this process "resource development," which I have termed, in an earlier report to the Court, "the key and principal engine of compliance" with the consent decree. Findings and Recommendations of the Special Master, June 2, 1980, at 10.

In June 1980 we sought from Pineland Center the number of Pineland residents who had been recommended for community placement by interdisciplinary teams. The information was not available. The number of Pineland residents in need of a home was not being compiled. Information on the kind of homes, programs, and support services called for by interdisciplinary teams was not being collected. The regional offices of the Bureau of Mental Retardation, which have the responsibility for resource development, did not know what the community-placement needs of Pineland residents were. Community service workers were not being assigned to individuals who had been found to be capable of living outside the institution if the proper programs and services were provided. In short, no one knew the dimensions of Pineland residents' current need for community homes. It is essential that this information be known. It serves both as a guide for planning resource development, including preparing budget requests, and as a measure of the state of compliance with the Court's decree. For these reasons, the decree requires the State to establish "a data system of client needs and of availability of services in the community" including "[t]he needs of residents of Pineland for community services or placement." Appendix B, §C.12. In the absence of such information, we requested and received a copy of each Pineland resident's individual plan and have here compiled the information they contain on community-placement needs of Pineland residents.

## III. ANALYSIS OF PLACEMENT RECOMMENDATIONS

Individual prescriptive program plans were received for 338 Pineland residents. Community placement recommendations were not made in 9 cases, usually because the interdisciplinary teams had been convened to consider a single, unrelated issue. The remaining 329 plans all addressed the issue of community placement. Of this number 313 Pineland residents have been found by their interdisciplinary teams to be capable of leaving Pineland for homes and programs in the community as long as the proper support services are provided for them by the State. In other words, ninety-three per cent of Pineland residents have been recommended for placement in community homes. Only 16 residents were recommended to remain at Pineland for the foreseeable future. (If a plan were ambiguous on whether an individual had been recommended for placement, the plan was counted as not recommending placement. Thus, the total of 313 recommendations for placement is, if anything, conservative.)

In the usual case, Pineland interdisciplinary teams give comprehensive and thorough consideration to community placement. Most recommendations for placement describe the characteristics of community homes best suited to each resident's needs. Nearly all plans describe any necessary special features of the home. Nearly all describe with particularity the programs and services which the State must provide for the resident to enable him to move from Pineland. Some recommendations also specify a preferred location for placement.[1]

### A. CHARACTERISTICS OF HOMES

The following table presents Pineland's 313 placement recommendations by type of home required.

* 214 Residents need an ICF-MR group home or group home of comparable quality.[2]

---

[1] "Each resident shall be placed in a placement as close as practicable to the area in which his correspondent lives." Appendix B, § A.2.(c). Many interdisciplinary team reports state that the resident may be placed "statewide" because there is no family involvement. Where the team failed to note a preferred location for placement, it was assumed that none was intended. These were counted as "statewide" recommendations.

[2] "ICF-MR" is a designation in federal law setting out criteria by which homes for the retarded may become eligible for federal funds. It stands for Intermediate Care Facilities for the Mentally Retarded. In order to achieve ICF-MR licensure, homes must meet federal standards. The State is now in the process of converting 22 group homes to ICF-MR status as a result of the Master's recommendations of December 24, 1979. This conversion will not create any new openings for placement.

* 49 residents need a nursing ICF-MR.[3]

* 28 residents need a group home but could also live in one or more of the following: a nursing ICF-MR, foster home, or boarding home.

* 2 residents need foster care.

* 2 residents need boarding care.

* 1 resident could return to live with his parents if support services were available.

* 16 recommendations failed to specify the type of home needed.[4]

B. SPECIAL FEATURES OF NEEDED HOMES

* 224 residents, 72% of those recommended for placement, need a home which can carry out effective instruction in adult daily living skills. Such instruction includes basic self-care tasks such as dressing, toileting, grooming, personal hygiene.

* 196, or 63%, need homes which have consulting therapists. The list of professional consultants includes nurses, psychologists, occupational therapists, physical therapists and speech clinicians.

* 103, or 33%, need a home which can carry out behavior-intervention programs to deal with aggression, self-abuse, abnormal behavior, and the like.

* 38 need a home where they can be instructed in home-life skills.

* 25 of those recommended for placement need a home where staff and residents communicate with sign language.

* 18 residents need a home for the blind or the visually impaired.

---

[3]State ICF-MR regulations, draw a distinction between homes designated as either "group ICF-MR" or "nursing ICF-MR." The principal distinctions between the two are the medical needs of residents and the staffing requirements imposed. In reviewing the individual plans, it was not always clear whether the team was recommending a home with nursing staff or only nursing consultants. In the latter case a group home placement would suffice. Such recommendations were cross-checked with the program plan's medical report. If the medical report indicated a need for close medical monitoring, it was assumed that a recommendation for placement in an "ICF" was a recommendation for placement in a "nursing ICF-MR." Many of these recommendations were made before the new state regulations created the distinction.

[4]Occasionally, one encounters placement recommendations which fail to label the needed residence as a "group home," etc., yet provide a good description of what the home should be like. Almost always these descriptions show conclusively that a group home was intended. Only when the team's intent could not fairly be ascertained was the recommendation counted as a failure to specify.

* 3 people clearly need a "dual-diagnosis" home, i.e. a home for persons who are both mentally retarded and mentally ill. Three such homes now operate in the Bangor area.[5]

* 1 individual needs a single-sex home.

C. PROGRAMS

Community placement recommendations are accompanied by recommendations on the kinds of program which the State must provide to support home placement. Program recommendations are summarized here.[6]

* 112 of the 313 Pineland residents recommended for placement need a day activities program. This term refers to a variety of developmental activities provided in sequence to adults with relatively short attention spans.

* 106 need communications programs. This term includes both verbal and non-verbal forms of communications. Some individuals communicate with pictures, gestures, facial expressions, or electronic devices. Programs are designed to increase their ability to use these techniques.

* 116 need therapy conducted by professionals. This does not include programs to be designed by professionals and executed by paraprofessionals or others.

* 14 need a program for the blind.[7]

* 220, or 70%, need recreation which provides social interaction or community exposure.

* 68 residents need a pre-vocational program. The purpose of a pre-vocational program is to maximize individual functions and personal development through regular work experience at an introductory level.

* 20 need sheltered employment. Sheltered employment is continuous paid employment for individuals not capable of functioning in a competitive work force. Competitive work pressures are reduced.

---

[5]It seems probable that many of the 103 individuals recommended for behavior intervention homes really need a dual-diagnosis home. The teams may have intended the latter while specifying the former. In any case, the behaviors necessitating the recommendation are always clearly spelled out in the individual plan.

[6]There is no overlap in the figures reported above and those reported here under "program." Occasionally, a placement recommendation states the kind of programs currently being provided as those the resident will need in the community. Such recommendations were cross-referenced to the plan's program section in order to tally the programs specifically intended.

[7]It is not clear why 18 residents need a home for the blind, yet only 14 were found to need a program for the blind.

* 89 need fine or gross motor exercises. Fine motor activities increase fine hand skills or control of other small muscles. Gross motor activities improve total body movement.

* 57 need sensory stimulation. These exercises stimulate any of the five basic senses or the vestibular (inner ear) system.

* 9 need positioning. This involves placing an individual in a more functional position, perhaps to prevent scoliosis (curvature of the spine) or to reduce a tendency of the entire body to extend involuntarily.

* 32 individuals need to be taught community survival skills. This instruction includes making purchases, using transportation and traffic safety.

* 64 need education.

* 21 need a program specifically addressed to behavior modification. This need is distinct from the need for a home providing behavior intervention.

* 11 need a geriatric program. This is usually described as low-intensity, recreational activity of reduced duration.

* 2 residents need either day activities or pre-vocational program.

* 1 resident needs day activities or sheltered employment.[8]

* 1 resident needs farm chores as his program.

D. LOCATION PREFERRED

Many Pineland residents have concerned families taking an active interest in their welfare. Location preferences in placement recommendations usually reflect family involvement. Placement recommendations thus attempt to facilitate continued family contacts by placing a resident in that region of the Bureau of Mental Retardation where his family lives.

The following table shows the preferred locations of the 313 recommended placements by Bureau Region.

| BMR REGION | NUMBER OF PLACEMENTS |
|---|---|
| I (Presque Isle) | 4 |
| II (Bangor) | 19 |
| III (Augusta) | 14 |
| IV (Lewiston) | 22 |
| V (Portland) | 61 |
| VI (Thomaston) | 11 |

[8]This is probably a mistake. The skills required for these programs are diverse, representing very different developmental levels.

Some preferences are given in the alternative:

| | |
|---|---|
| I or II | 1 |
| III or IV | 5 |
| IV or V | 9 |
| V or VI | 4 |
| Any of 3 BMR Regions | 5 |

158 of those recommended for placement could be placed "statewide" according to their interdisciplinary team reports.

E. OBSTACLES TO PLACEMENT

Virtually all community placement recommendations contain assessments, made by interdisciplinary teams, of the barriers to placement. The plans state exactly the obstacles that stand in the way of immediate placement into community homes and that prevent Pineland residents from realizing their right to noninstitutional living. The answer is not usually anything intrinsic to the person; nor is it usually any failing on the part of Pineland Center. In the overwhelming number of cases the sole obstacle to placement is the lack of community alternatives:

> "There are no existing homes to meet B's needs."
>
> "Lack of facilities providing the services and level of care needed in terms of residence and program."
>
> "Lack of services and facilities."
>
> "Currently such a facility does not exist."
>
> "There is no such program currently available."

Thus, we come, once again, to the key and principal engine of compliance of the Court's decree: resource development. The sole reason why most Pineland residents are not now living in homes in the community is the insufficient number of homes which would meet their needs.

Moreover, the information which is necessary to planning resource development and formulating budget requests has been, until now, buried in the records of Pineland Center. Contrary to decree requirements, that information has not been previously compiled and has not been disseminated to those in charge of resource development. In short, the State does not know the extent of the class members' unmet needs for new homes, new programs, and new services.

F. OBSERVATIONS ON ANALYSIS

1. Pineland Center. An obvious conclusion to be drawn from the foregoing analysis is that the individual-planning process at Pineland is working. We reported last year that Pineland was an obstacle to placement. See Report of the Special Master, Nov. 14, 1978, part II, at 138 et seq. In contrast, we can now report that interdisciplinary teams are routinely addressing each Pineland resident's right to move from the institution to the community. Program plans prepared by interdisciplinary teams contain a complete inventory of the kind of new homes, programs, and support services which the State is obligated to provide under the decree. The results of the foregoing analysis constitute both a mark of Pineland's progress toward compliance with the decree and a measure of what still remains to be done by the State.

2. Data Collection. The decree specifically requires the State to compile information on unmet client needs and, more importantly, to establish a system whereby such information can be continually brought to light and constructively used.

> The defendants shall develop a data system of client needs and of availability of services in the community. An annual report shall be prepared listing . . . the number of clients currently in need of service and the type of program each needs . . . [including] [t]he needs of residents of Pineland for community services or placement. . . . [Appendix B, § C.14.]
>
> The number of [Pineland] residents in need of a service which is not currently available and the type of program each needs shall be compiled and these figures shall be used to plan for the development of new services and programs. [Appendix A, § D.4.]
>
> The number of clients in need of a service which is not currently available and the type of program or residential placement each needs shall be compiled and these figures shall be used to plan for the development of new programs and residential placements. See Appendix B, Section C, paragraph 14 [cited above]. [Appendix B, § B.4.]

In contrast to decree requirements, the information contained in this report has not previously been compiled. The State has no system for collecting data relevant to decree compliance. A data system is indispensable to reaching full compliance, to maintaining compliance once achieved, and to enabling the Court to be informed of the State's progress toward compliance.[9]

---

[9] The State did evaluate prescriptive-program planning in the community and found aspects of the process in need of change. See Report of the Special Master, April 22, 1980 footnote at 7. A state-wide

(footnote continued on next page)

3. Planning. In the absence of the kind of information compiled in this report, the State cannot be expected to be accurate either in planning new resource development or in preparing budget requests sufficient to finance the community side of the decree. A reasonable doubt about the accuracy of the State's fiscal requirements is inescapable. The remedy is to compel compliance with the above-quoted decree provisions and all other information-gathering and reporting provisions of the decree and to compare the results with all available budget documents. Only then can doubts be resolved about whether the State even has the capacity to come into compliance with the consent decree.

---

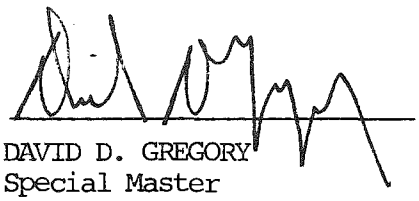
(footnote continued from previous page)

"unmet needs" survey (not including Pineland Center) conducted from December 1979 to February 1980, see id. at 5, 75, 77, yielded seriously flawed results and is not now planned to be repeated. A state-wide "case record review" (not including Pineland Center) is now being completed and its results are expected to corroborate the accuracy of the Master's April 22nd report. The State is not going to use the case-record review for establishing a data-collection system but plans only annual updating on the basis of random sampling. None of these efforts meets, in any event, decree requirements.

## IV. CONCLUSION

The foregoing report is submitted to the Court in partial fulfillment of the obligations owed to the Court by the Special Master.

Respectfully submitted,



DAVID D. GREGORY
Special Master

ARTHUR R. DINGLEY
Assistant to the Special Master

Dated: November 24, 1980
Portland, Maine

Professor David D. Gregory
University of Maine School of Law
246 Deering Avenue
Portland, Maine 04102

# APPENDIX I

## RECOMMENDATIONS FOR PLACEMENT

To illustrate both recommendations for and against placement, we include as exhibits exerpts from a number of Pineland individual plans. Appendix I contains representative recommendations favorable to placement. Appendix II contains representative examples of recommendations against placement. The exhibits are simply that page (or, in some cases, two pages) of the individual plans which contains the section pertaining to community placement. The plans were prepared by interdisciplinary teams which included professionals from a variety of disciplines and those direct-care aides who are most closely familiar with the needs and capabilities of individual residents. The exhibits contain the judgment of interdisciplinary teams on the community-placement needs of Pineland residents. Taken as a whole, the plans constitute the most complete catalogue yet compiled of what the State must do to fulfill the right, guaranteed to Pineland residents by the consent decree, to live and learn in the least restrictive environment.

PINELAND CENTER

CASE NO. 3903 NAME W J

YEAR NO. 197

INTERDISCIPLINARY TEAM REPORT Page 2

COMMUNITY PLACEMENT

The following components have been identified as pre requisites for placement:

A. Environment/Services

1) The ideal setting would be one that provides services to the blind
2) A daily day activity program on a full day basis
3) Continued emphasis on ADL skill training
4) Access to Occupational Therapy consult
5) Access to Physical Therapy consult
6) Access to Orthopedic consults
7) Access to Speech Clinician on a consultive basis

B. Barriers

1) Lack of services and facilities

PINELAND CENTER



CASE NO. 3780 NAME H R

YEAR NO. 74 DOB 8/14/58

INTERDISCIPLINARY TEAM REPORT

III

| STRENGTHS | NEEDS |
|---|---|
| -sociable, enjoyable, likes people | -Communication Evaluation |
| -enjoys her day program | -increase program time and pre-vocational content |
| -healthy | -needs more adult home-like environment |
| | -needs refined personal care training |
| | -physical and recreational activities |

IV COMMUNITY PLACEMENT

1. Environment/Services
   - -small group home with 24 hour supervision
   - -age appropriate activities with adult role modeling
   - -homelike environment
   - -Communication Services
   - -Task Analysis or otherwise concrete and specific teaching technologies available for ADL training

2. Location
   Region IV or V though not to exceed a 50 mile radius of Pineland Center.

3. Type of supervision
   2,6 staff to client ratio

4. Program
   - -6 hours daily, 5 days per week with emphasis on pre-vocational skill development
   - -Communication Therapy
   - -Recreational and social activities evenings and weekends
   - -specific refinement training in ADL

5. Barriers
   There are no such placements currently available

V CERTIFICATION

-That R H is Mentally Retarded.
-R does require services of an intensive nature.
-Pineland Center is the least restrictive alternative available at this time to our knowledge.
-Services are available at Pineland.
-R is not able to voluntarily participate in the admissions process.

PINELAND CENTER

CASE NO. 4367 NAME J D

YEAR NO. 42



COMMUNITY PLACEMENT

An ideal sitting to address D 's needs was described as follows;

1. A small residential setting servicing adults
2. Services of a psychologist/psychiatrist on an on-going basis
3. Services of a trained communication therapist
4. Training in pre-vocational/vocational skills
5. All services provided with a small resident to staff ratio

Due to the complexities of D 's needs, this team felt that such a residential/educational setting was required. In addition, the placement needs to provide D with a highly structured millieu.

Barriers to placement are; the lack of such facilities that will provide services for individuals functioning at D 's level.

COURT CERTIFICATION

This team felt that D was innappropriately placed at Pineland. This setting it was felt, could not provide, to the intensity required, all the habilitative intervention D required.

D 's parents expressed strong reservations regarding D 's placement outside of Pineland.

IV. COMMUNITY PLACEMENT

A. Environment/Services

1. Residence - Should be an ICF/MR structure designed to guarantee consistancy in - a) program carry over b) providing leisure time

2. Location - Preference would be given to Region IV. Lewiston-Gardiner area.

3. Supervision - 1:4 ratio. Intense supervision

4. Programs

a. O.T.: 3½ hour sessions weekly by OTR with goals of sensory stimulation gross motor development, and increasing protective responses.

b. P.T.: 15 min. sessions by an RPT with goals of heelcord stretching and improved ambulation.

c. Educational - 6 hr. programming daily M-F partially outside of residence.

d. Communication, Medical, Psychological and social worker consulting.

e. Leisure/Recreation. One event of each in community weekly.

B. Barriers

Currently such a facility does not exist.

C. Currently Pineland is meeting B needs to the best of it's ability but not entirely. A community resource that could partially meet her need would be considered per review of the IDT.

D. Time frame: A target date of January 1981 set.

V. CERTIFICATION REQUIREMENTS

The IDT determined that B is retarded, requires treatment of an intensive nature. Pineland is, at present, the most appropriate site and is meeting her needs to the best of it's ability. B is unable to voluntarily participate in the admissions process.

B was last certified on 5/17/78 for 24 months.

PINELAND CENTER

CASE NO. 5163 NAME K S

YEAR NO.

INTERDISCIPLINARY TEAM REPORT Page 4

IV. COMMUNITY PLACEMENT

A. Environment/Services

1. A young adult ICF/MR program oriented statewide
2. Daily educational program outside the residence
3. Direct Occupational Therapy by OTR 3 x weekly for ½ hr. sessions
4. Physical Therapy 4 x weekly for ½ hr. sessions by PTA with RPT consult.
5. Communication Therapy twice weekly stressing communication board use.
6. Daily ADL training
7. Recreational and community interaction events once weekly

B. Barriers

There is no such program currently available.

C. Target date for placement - 2/20/81.

D. Comments: If a community placement that would partially meet S needs were available it would be considered per review of the IDT.

V. DISCUSSION

Discussion focused on S recent dispoition change from happy and outgoing to withdrawn and unhappy. This was thought to be attributed to his recent loss of close staff relationship from job changes, to his becoming less appropriate age-wise and developmentally at BH, and to his receiving less attention as "the baby" and being treated more as a young adult on the unit. It was noted that he needed increased physical therapy intervention, increased O.T. therapy, more community/ recreational and leisure time activities and to continue other current programming.

COMMUNITY PLACEMENT CONSIDERATIONS:

The team has identified the following components as being necessary in order to place C in a community setting:

1. ICF-MR facility in Region 5
2. Staff with expertise in handling behavior problems
3. Adult Day Activities Program
4. Occupational Therapy on a consultant basis
5. Recreational opportunities
6. Consulting Psychologist available
7. Opportunity for community experiences

BARRIERS TO PLACEMENT:

1. Unavailability of ICF-MR facilities for adults with behavior problems.

COMMUNITY PLACEMENT ANALYSIS

A. RESIDENCE: TYPE, LOCATION, LEVEL OF SUPERVISION: M would need an ICF-MR facility which could cope with her smearing behavior. BMR is her guardian, so she could be placed statewide. She would require a 1-to-4 staffing ratio.

B. PROGRAMS: (1) A.D.L., (2) Day Activities, (3) Occupational Therapy, (4) Communication, (5) Social/Recreational.

C. SUPPORTIVE SERVICES: Medical follow up because of history of seizures (well controlled at the moment).

D. COMMENTS: Other than her smearing, M is an easy resident to work with. Her behavior has improved recently, and she is sleeping better.

E. BARRIERS: Unavailability of ICF-MR facilities.

F. TIME FRAME: REVIEW, PLACEMENT: M is certified through 10/25/80. It seems unlikely that sufficient ICF-MR facilities will be developed for profoundly retarded adults by that time, therefore the Team suggests 24 months re-certification.

DISCUSSION:

M sometimes hyperactive behavior appears to be cyclic in nature. Her primary aide suggested that this might be associated with her menses. Usually she is quiet during menses, then her behavior starts to build up just before her next period.

M is edentulous, and the question of dentures was raised. It was thought that it would be doubtful if she would keep them in her mouth, then when she took them out she would probably play with them and throw them as she does with toys.

The question of a transfer to a quieter, slightly higher functioning unit was discussed. It was felt that she might benefit from being with peers who were all toilet trained (perhaps eliminating her smearing), but on the whole she seems to fit in with her present peers.

PINELAND CENTER

CASE NO. 4008 NAME W D

YEAR NO. 38 DOB: 1/3/59

INTERDISCIPLINARY TEAM REPORT Page 4

IV. COMMUNITY PLACEMENT

1) Environment/Services

a. Medical per seizures
b. Occupational Therapy (3 x's weekly)
c. Recreational Services
d. Church
e. Communication Therapy

2) Location

Statewide

3) Type of Supervision

2:6 staff to client

4) Program

a. Full day of programming to include:

- Occupational Therapy
- Communication therapy
- ADL training
- Pre-vocational training
- Community awareness training

5) Time frame for placement

As soon as an appropriate placement can be found

6) Barriers

None presently exists.



V. CERTIFICATION

D is Mentally Retarded. He requires services of an intensive nature. Pineland is the least restrictive environment available at this time. The services D requires are provided here at Pineland. He is not able to participate in the admissions process. D was recertified on 9/13/79 for 24 months.

VI. DISCUSSION

D M 's mother has volunteered to be D 's correspondent. When D 's new curriculum has been developed Carl Scott will share with us the task analysis he has developed for D .

RESIDENCE: TYPE, LOCATION, LEVEL OF SUPERVISION:
ICF-MR or a small group home for profoundly retarded adults; Region II (sister, guardian, resides there); 1 - 4 staff ratio.

PROGRAMS: 1.) Continuing ADL (eating, toileting, dressing);(2.) Day Activity (sensory stimulation, gross motor). 3.) Communication stimulation. (4.) Recreation (walks, pool, van rides, trips). (5.) Socialization (small group parallel games, music).

SUPPORTIVE SERVICES: O.T. consult on once a month basis; routine medical intervention as needed.

COMMENTS: Behaviorally, B seems to have improved, i.e. very little self-abuse, relates somewhat better.

BARRIERS: Lack of suitable facilities for profoundly retarded adults.

TIME FRAME: REVIEW, PLACEMENT: Certified through 2/28/82; quarterly review.

DISCUSSION: Application for admission will be made for the Treats Falls residential facility and the multiply handicapped center (day program). The MR Caseworker will prepare these applications by August 31, 1980.
The RN will ask for review and possible discontinuance of PRNs for insomnia and aggression.
The team felt B could benefit from full day programming. Her Primary Aide felt B should be involved with smaller groups (four or less). The Team felt program emphasis should be toward a low stimulus group.
A Baking Soda program to eliminate or diminish mouthing behavior to be reinstituted and be reviewed at B 's next quarterly. Baking soda is to be applied oonsistently after all meals and snacks; the effectiveness of program to be charted in B 's nursing notes.

PINELAND CENTER

CASE NO. 2543 NAME W B

YEAR NO. 114

INTERDISCIPLINARY TEAM REPORT Page 3

| III. STRENGTHS | NEEDS |
|---|---|
| - has interested and involved parents | |
| - uses toys appropriately | |
| - follows verbal and gestural directions | - hearing evaluation and direct communication therapy |
| - vocalizes pleasure and distress and smiles | - encourage her helping herself and others |
| - she is affectionate: calls for others and enjoys helping and being needed | - more appropriate living unit peers of like developmental level and training in home and work skills |
| - is well adjusted and has a good self image | |
| - has a good sense of humor | |
| - greatly enjoys community trips | - continue community trips, church and recreational activities |
| - is semi independent in dressing, toileting, bathing, toothbrushing and eating | - continued ADL training |
| | - appropriate leisure time activities |
| - is generally healthy | - a hair permanent |
| | - hankerchiefs to pin on shirt |
| | - new clothing picked out by her |
| | - toilet articles |

IV. COMMUNITY PLACEMENT

A. Environment/Services

1. Residence: Group home with six to eight residents structured to teach household skills, provide leisure, recreational and community activities.

2. Location: Region V due to family involvement.

3. Supervision: 1:4

PINELAND CENTER

CASE NO. 2543 NAME W B

YEAR NO. 114

INTERDISCIPLINARY TEAM REPORT Page 4

4. Programs:

ADL skills training with O.T. consult
P.T. at least monthly consult for braces
Direct communication therapy weekly
Working and domestic skills development program
Programs off unit daily
Leisure and recreational events weekly

B. Barriers: There is no such appropriate residence available at this time.

C. Comments: If a community facility became available that could partially meet the above needs it will be considered per review of the IDT.

D. Time Frame: February 1981.

V. DISCUSSION

The team focused on B social interaction skills and her need for us to encourage her expression of these. We agreed that all staff would encourage her to help others and provide her with leisure time activities related to home living skills which she greatly enjoys. She also has a strong preference for certain clothing items and should be allowed to choose her own clothes. Her strong individual personality traits were admired by the group and we agreed to allow her expression of these at every opportunity.

PINELAND CENTER

CASE NO. 5353 NAME P J

YEAR NO. 20 DOB 9/23/71

INTERDISCIPLINARY TEAM REPORT

III

| STRENGTHS | NEEDS |
|---|---|
| -personable | -continued participation in outings and social activities |
| -basically healthy | -close monitoring of seizure activity and medications |
| | -psychological services on an as needed basis |
| -has made great progress in areas of personal hygiene and eating skills | -refinement training in all of these areas |
| | -warm and nuturing homelike environment |
| | -to learn to utilize leisure time |
| -enjoys school | -daily school program providing the same curriculum utilizing the same techniques |
| -enjoys, benefits from and is making progress in all his therapy sessions | -continued therapy sessions in all three areas |

IV

COMMUNITY PLACEMENT

1. Environment/Services
   - -homelike nuturing environment
   - -Occupational Therapy Consult Services
   - -Physical Therapy Consult Services
   - -Communication Therapy Consult Services
   - -Personal Hygiene Program Services
   - -Psychological Consult Services
   - -Seizure Specialist - Services

2. Location
   Region V

3. Types of Supervision
   2:6 staff to client ratio

4. Programs
   Day program
   1) A day program should provide at minimum what J receives at Berman School:
      a) OT, PT and Communication therapy sessions
      b) Transdisciplinary curriculum planning
      c) Precision teaching methods
      d) Home carryover and communication
      e) At least 30 hours per week

CASE NO. 5353 NAME P J

YEAR NO. 20 DOB 9/23/71

INTERDISCIPLINARY TEAM REPORT

IV COMMUNITY PLACEMENT (continued)

Home training
1) Refinement training in the areas of personal hygiene and eating
2) Training in use of leisure time
3) Field trips and outings as set forth in the Consent Decree
4) Training in household tasks

5. Comments
J was originally placed at Pineland Center for training in the areas of personal hygiene and eating. Once he had accomplished programming criterion he was to return home. Those goals set forth have now been met and J is ready to return. J 's family is willing to have him return home, but there is not a day program to accommodate him in the Kittery area, thus prohibiting placement.

6. Barriers
The non-existance of an appropriate day program in the Kittery area.

V DISCUSSION

J 's seizure activity has been of much concern to all involved as reflected in the reports. I invited Dr. Holt to the IDT to share information with us. Since J 's stay in Benda, Dr. Holt has changed his medication and feels that his seizure activity has decreased considerably. He will return to the Cottages in a few days and be seen in Seizure Clinic in three weeks. People will keep a close watch to see how he is progressing.

J 's placement was discussed and the situation remains the same as outlined in the Synthesis that he would return home as soon as a day program could be found. The P 's do not object ot a community home placement but much prefer J to be with them if at all possible.

Mrs. P also stated that she was quite pleased with the work of the Cottage I staff and the Berman School staff and felt that J had come a long way. It is important to the P 's that any community day program or community home be equal to or better than the care and training J is receiving at Pineland.

PINELAND CENTER

CASE NO. 2975 NAME W F

YEAR NO. 68

INTERDISCIPLINARY TEAM REPORT Page 4

him at the upper end of the Profound range of retardation for social adaptive functioning. There are indications of some slight gains in developmental skill expression over most recent findings.

III. STRENGTHS

- has a guardian
- is able to communicate his needs
- enjoys community trips
- Independent in mobility of grounds
- relates to peers and staff
- is in good health
- helps out on the unit
- enjoys recreation activities

NEEDS

- 6 hours programs
- continue at ADAC
- continue community trips
- medication review every 2 months
- continue ADL training
- community placement or unit at Pineland (as outlined in Community Placement Section)

**PRIVILEGED AND CONFIDENTIAL NOT TO BE USED AGAINST PATIENTS INTEREST.**

IV. COMMUNITY PLACEMENT

A. Environment/Services

1. Residence - F needs a structured, benign six bed group home with appropriate peer group. The home staff should be able to deal and respond to E occasional aggression. Structure should be designed to guarantee consistency to foster independence in ADL, leisure time activities and provide an activity program outside of the home.

2. Location: E could be placed statewide.

3. Programs:

   a) ADL: E needs to continue with hair combing, bathing skills, and neatness in appearance.
   b) Activity Center: E needs a full day of programs but within the program only a half day of scheduled classroom time and the other half a day group activities (i.e. gym, bowling, leisure activities)
   c) Community Survival: E needs to generalize his limited mobility skills to a community setting. In doing so he would have to be aware of traffic, sidewalks, using public facilities (correct bathrooms) and use of money, to name a few.

PINELAND CENTER

CASE NO. 2975 NAME W E

YEAR NO. 68

INTERDISCIPLINARY TEAM REPORT Page 5

d) Socialization/Recreation: E needs to learn to interact appropriately with staff and peers. He also needs exposure to variety of developmentally appropriate community activities.

B. Barriers: Some of the services E would need are in the traditional community setting but he does present a behavioral problem occasionally and home operators would have to respond and deal with his upsets when they arise.

C. Time Frame: Status of placement potential should be reviewed at 4/80 at quarterly review.

V. CERTIFICATION REQUIREMENTS

E was certified through District Court on 5/30/78 for a period not to exceed 24 months. The team recommends a re-certification of 24 months.

VI. DISCUSSION

The IDT met today to discuss E W a resident of Doris Anderson Hall II. E still has, at times, behavioral upsets but they are not as frequent as they have been in the past. He continues to verbalize threats and sometimes goes through with them (i.e. "I'm going to push you or kick you." The DAH 2 staff deals with this behavior by intervening and sending him to his room for a period of 10-20 minutes to calm down. This method has been effective with E At ADAC the staff state E hasn't been a problem but if he does become upset they usually take him from the situation to a quiet area to calm down also for 10-20 minutes. There was a question of whether E could tolerate six hours of classroom schedule time. The team agreed E could benefit from more programming but in the area of group activities, at the Leisure Center or gym. DAH 2 staff to see E gets involved in these activities during the afternoon. E only has to be told to go to these areas to participate. Dr. Monroe added that E had made some slight gains in developmental skill expression over most recent findings.

The team also discussed at great length alternate placement. At the present time, the team could not agree on a building at Pineland that would be better than DAH 2 for E However, community placement was discussed and the team agreed if a place could be found for E in the community as described in Section IV he should be placed or if a building at Pineland was developed like Section IV E should be placed there. Jack Marsh, Social Worker, stated he would look into locating a community placement if that was what the team wanted. The team all agreed to placement.

PINELAND CENTER

CASE NO. 2062 NAME W F

YEAR NO. 29 D.O.B. 8/29/37

INTERDISCIPLINARY TEAM REPORT Page 4

IV. COMMUNITY PLACEMENT

A. Environment:

1. Residence: P would be a suitable candidate for an ICF-MR facility.

2. Location: Statewide.

3. Type of Supervision: Regular ICF-MR (1 to 4 ratio) would be sufficient, for F presents few behavior problems. She sleeps very little at night, so night time coverage should be at least 1 to 10 ratio.

B. Programs:

1. A.D.L.: P needs to refine her eating skills and to learn how to use a fork. She should be encouraged to be more independent in her dressing, and maintained on a scheduled toileting program.

2. Day Activities: F needs to increase her tolerance to programming, to independently make marks on a paper with a crayon, to independently complete an obstacle course, to independently brush her hair, and to be able to string a 20 small bead necklace.

3. Communication: P needs daily work on awareness and reduction of self-stimulatory behavior by residence staff under the supervision of an O.T. or a qualified speech pathologist.

4. Occupational Therapy: P needs to improve her concentration through body awareness activities, to be provided with a variety of tactile experiences to satisfy tactile and oral needs, to be involved in small groups to improve social skills, and to use the hammock and swaddling as relaxation techniques for agitated behavior.

5. Social/Recreational: P needs regularly scheduled activities to increase her interaction with peers/staff, and to help her relax (i.e. a pool program). She should be involved with daily activities by staff, with consultant services.

C. Comment: P can be very affectionate with staff, putting her arm around them independently or taking their hands. For the most part she can be a pleasant person to work with, although her sleeplessness can cause problems at night.

D. Barriers: Presently there are few ICF-MR facilities available; the caseworker is unaware of any vacancies even though F could be placed statewide.

PINELAND CENTER

CASE NO. 2062 NAME W P

YEAR NO. 29 D.O.B. 8/29/37

INTERDISCIPLINARY TEAM REPORT Page 5

IV. COMMUNITY PLACEMENT (Cont.)

E. Time Frame: P is certified through 9/26/80. The Team is unaware of any ICF-MR facility vacancy which might be available to P and would suggest re-certification for another 24 months, by which time more community ICF-MRs should become available.

V. CERTIFICATION CONSIDERATIONS

P is certified until September 26, 1980. She is a profoundly retarded individual, who requires treatment of an intensive nature, see Section IV above. At present Pineland is the least restrictive and most appropriate treatment site available for P The treatment she requires is available at Pineland. P is unable to participate voluntarily in the admissions process. The Team recommends recertification for 24 months.

VI. DISCUSSION

Presently the Team's greatest concern about P revolved around her sleeplessness. She is on Noctec PRN for this behavior, since she can get very agitated and slaps herself when she doesn't sleep. Since October 12th, she was given Noctec 6 times in October, 7 times in November, and twice in December (11 days). The L.P.N. suggested that perhaps a medication regime could be started to make her go to sleep regularly, and then she could be gradually withdrawn from it, but the Team was reluctant to take this approach. Rather the suggestion was made that she could use the hammock for relaxation or she could have an evening pool program. It was noted that the hammock has not been put back up since the remodelling.

P also indulges in quite a bit of self-stimulatory behavior, which should be directed into more appropriate channels. For example, she likes to play with paper, and thus can be encouraged to make marks on it with crayons, rather than just rustling it.

Her primary aide noted that P is being encouraged to pick out her own clothes in the morning, and that she does go through them (not just selecting the article on top) and does try to "color coordinate" her pants and tops.

The Team agreed that P would be a suitable candidate for community placement in an ICF-MR facility. Because BMR is her guardian, and her relatives live out of state, she could be placed in any Region. She was suggested for the Treats Falls facility, but one of their admissions criteria was to have an interested family living in Region II, so she is not being considered there.

[Second of Two Pages]

IV. COMMUNITY PLACEMENT

A. Environment/Services

1. Residence: A pediatric ICF/MR, preferably co-ed. Ability to provide carry over of programming.

2. Location: Region V.

3. Supervision: 1:4

4. Programs



O.T. - provided by OTR ½ hr. 3 X weekly.
P.T. - provided by PTA 5½ hr. sessions weekly.
Communication Therapy - provided 3 x weekly
Recreation/Leisure - structured appropriate trips 1-2 times weekly.
Structured leisure time activities.
ADL - Consistent program carry over from O.T. and educational
Educational Programs - off the unit and on at least 6 hrs. daily.

B. Barriers: There is no facility available at present that could meet these needs.

C. Comments: If a community facility were available that could meet some of these needs placement would be considered per review of this IDT.

D. Time frame: January 1981 or as soon as possible.

V. CERTIFICATION

S was certified on 3/7/78 for 24 months. Although Pineland is meeting her needs to the best of it's ability, if an appropriate community placement were available (described above) she should be placed in the community.

VI. DISCUSSION

Major points of discussion were S need to continue formal programming as is, adding consistant carry over in all areas, her need for more appropriate leisure time activities and her need for new equipment. She seems to be well liked and content in her environment.

COMMUNITY PLACEMENT ANALYSIS

A. RESIDENCE: TYPE, LOCATION, LEVEL OF SUPERVISION: Small 6 bed group home statewide, which can handle self abuse problems constructively and continue with blind training, or ICF/MR. 1-4 staffing. Home training to maintain and continue hearing aid program.

PRIVILEGED AND CONFIDENTIAL
NOT TO BE USED AGAINST
PATIENTS INTEREST.

B. PROGRAMS: (1) ADL, (2) Continued Blind training, (3) Pre-vocational & pre-academic, (4) Communication therapy (by speech pathologist or someone under direct supervision), (5) Social/Recreational.

C. SUPPORTIVE SERVICES: Psychological intervention for self-abusive behaviors.

D. COMMENTS: D has come a long way toward controlling her self-abusive behaviors since she has been on a 100% contingency time out with chair restraint behavior management program.

E. BARRIERS: Unavailability of suitable community placement.

F. TIME FRAME: REVIEW, PLACEMENT: D is certified thru 2/21/82.

DISCUSSION:

rarely misbehaves in ADAC; if she digs, the procedure is to call the unit and she is icked up and returned to Bliss I. In Mr. Eastman's class it has been two years since she has ug herself. Both areas noted that noise in general can disturb her.

he Team addressed the issue of the time out chair restraint program, and means of possibly liminating it. The time she spends in the chair per episode has been gradually reduced from 5 minutes to 8 minutes. The Team felt that now is not the time to eliminate the use of the hair, i.e. it had to be used on Monday when she could not be dissuaded from banging her head, nd she was very good afterwards. The chair's use will be reviewed by the Rehab. meetings very two months. D is an extremely capable woman, with potential for more. The problem s to find enough meaningful tasks for her to do, particularly over the weekend. If the unit ad increased staff to provide D with more activities, this might also help to cut down on er self-injurious behavior.

he Resident Advocate had requested that the Team consider transferring D to a more appro- riate developmental grouping. Mr. Schmidt said that other units at Pineland had more activi- ies than Bliss I, and felt D could benefit from a transfer. Most of the Team felt that hanging her residence and the staff working with her might very well be detrimental to her ealth (behavior). Her behavior is tremendously better, and as it is stabilizing there should e no major changes in D living arrangements. This latter was apparently pointed out in certification hearing by the testimony of the outside psychologist (Philip Pierce,

h.D.).

16A

PINELAND CENTER

CASE NO. 4541 NAME W. S.

YEAR NO. 10

INTERDISCIPLINARY TEAM REPORT Page 4

IV. COMMUNITY PLACEMENT

A. Environment/Services

1. Residence: S would need an ICF/MR for young adults.

2. Location: Preference would be given to the Portland/Scarborough area due to family involvement.

3. Supervision: 1-4. Close monitor of seizures

4. Programs:

1. Full day educational program off unit.
2. Access to P.T. consult as needed
3. Access to O.T. consult as needed
4. ADL training



B. Barriers: Lack of facilities/services.

C. Comments: If a community placement that would partially meet the above needs were to become available it would be considered per review of this IDT.

D. Time Frame: As soon as an appropriate placement is available.

VI. CERTIFICATION REQUIREMENTS

S was certified as eligible for admission to Pineland Center on 5/31/78 for a period not to exceed 24 months. A renewal of like certification is appropriate.

VI. DISCUSSION

The team discussed S increased strength and ambulation and agreed that the removal of the chair restraint was appropriate. She is sleeping better at night than in November and December of 1979. Concern was voiced that the skin problem behind her ear may be caused by poor hygiene or use of the helmet when her hair was not completely dried. This is being monitored closely by the medical staff. It is the opinion of the team that when Berman School classes change that she may be more appropriately placed in a classroom with more ambulatory peers. The team decided that a change to a lighter weight face guard on her helmet would be beneficial and that the Occupational Therapy would pursue this.

PINELAND CENTER

CASE NO. 4681 NAME V C

YEAR NO. 5

INTERDISCIPLINARY TEAM REPORT Page 2

COMMUNITY PLACEMENT

The following components have been identified as necessary to achieve community placement.

A. Environment/Services

1. Highly structured group home geared for profoundly retarded adolescents/young adults. This home to have firm limits established.

2. An emphasis on ADL skill training.

3. Access to a daily educational program.

4. Access to Psychological consultation.

5. Access to consultive occupational therapy.

B. Barriers

1. Lack of facilities and services.

2. C 's attention getting behaviors.

CASE NO. 2320 NAME L M

YEAR NO. 55

INTERDISCIPLINARY TEAM REPORT - 1/24/80 Page4

IV. Community Placement

A. Environment/Services

1.) Residence - M needs an ICF-MR facility to monitor his seizures, preferably one floor due to M. seizures and unsteady gait, preferably a single room or roommate who would respect M truck collection.

2.) Location - Region II due to Mrs. 's consistent involvement over the years.

3.) Type of Supervision - Close medical monitoring due to seizures with a one to four staff ratio.

4.) Programs:

a.) Communication - In-house program is needed to teach M to follow basic commands as well as pointing to various environmental objects as they are named.

b.) Vocational - M needs a full day program consisting in activities to promote relaxation and decrease body rigidity, conceptual activities in preparation for prevocational tasks and teaching appropriate work skills so that he may become a candidate for a Pre-workshop setting.

c.) Community Survival - M needs to generalize current mobility skills from his residential area to program area to other areas (i.e. canteen program would eventually include traffic awareness, i.e. using sidewalks and crosswalks, and the use of public facilities.

d.) ADL - M needs intensive training in areas such as grooming, bathing, and shampooing.

e.) Socialization/Recreation - M needs continued exposure to a variety of developmentally appropriate community activities. M should also continue to have access to an area where his truck will be placed for his personal use.

B. Barriers: Currently the services outlined in the community section do not exist in Region II at this time. M seizures may also be a barrier.

C. Comments: M is an ideal candidate for community placement. He can entertain himself while unsupervised and is no behavior problem.

D. Time Frame: Status of potential placement should be reviewed by 5/3/80. Modified action plan for placement will be developed at this review.

V. Certification Requirements

M is a profoundly retarded individual, who requires treatment of an intensive nature. Pineland is the only, the least restrictive, and the most appropriate treatment site available to M at this time. The teatment that M requires is available at Pineland. M unable to participate voluntarily in the admissions process, and team recommends 24 months recertification.

PINELAND CENTER

CASE NO. 5119 NAME F S

YEAR NO. 57 DOB: 7/11/59

INTERDISCIPLINARY TEAM REPORT Page 3

| III. STRENGTHS | NEEDS |
|---|---|
| - has learned partially to eat on her own | - continue feeding program |
| - could learn correct toileting | - needs toileting program<br>- needs toilet |
| - participates in dressing process | - continue gradual participation on her part |
| | - needs daily medical care and consult for bowel discomfort and gyn examination |
| - S enjoys and benefits from her school program | - continue in her full day program at Berman |
| - S also enjoys and benefits from OT and PT | - continue in PT |
| | - continue in OT and 10 minute stimulation program |
| - S is a communicative person | - needs and enjoys communication with people |

IV. COMMUNITY PLACEMENT

1. Environment/Services

a) ICF/MR facility
b) O.T. Services
c) P.T. services
d) Psychological services by someone versed in self abusive behavior planning
e) Staff trained in above
f) Medical Services
g) Educational services
h) Recreational Therapy services

2. Location

Region III

3. Type of Supervision

1:3 staff/resident

PINELAND CENTER

CASE NO. 5119 NAME P S

YEAR NO. 57 DOB: 7/11/59

INTERDISCIPLINARY TEAM REPORT Page 4

4. Program

a) Intense programming via team effort (OT, PT, Psychologist staff) to deal with and be versed in areas of self abuse. A program much like the one S is currently on but to be more closely monitored.

b) Occupational Therapy Program to be carried out by an OTR at least 3 x's weekly

c) Physical Therapy program to be carried out by an RPT at least 3 x's weekly.

d) Recreational Program to provide physical activity and outings S enjoys.

e) Educational program to involve six hour day coverning the following areas: tactile stimulation, music, gym program and program to decrease reliance on restraints.

5. Comments

An ICF/MR facility dealing in self-abusive people would be best suited for S or a place where the above could be provided.

6. Time Frame for Placement

It is difficult to target a date as no facilities are even begun. 12/81 will be a tentative date.

7. Barriers

No such program currently exists in the state.

V. CERTIFICATION

That S P is Mentally Retarded.

She does require services of an intensive nature.

Some services are available at this time at Pineland

Pineland is the least restrictive environment at this time.

S cannot voluntarily participate in the admission process

VI. DISCUSSION

Considerable emphasis must be put upon the importance of S 10 minute stimulation program. In addition that time should be spent with someone with her restraints off in order to be real stimulation not time spent alone rocking or listening to a radio. [Second of Two Pages]

COMMUNITY PLACEMENT ANALYSIS

A. RESIDENCE: TYPE, LOCATION, LEVEL OF SUPERVISION: Small group home serving profoundly retarded adults with behavior problems, 1-4 staff ratio with 24 hour coverage, training in ADL, behavior, community survival. N should have opportunities for recreational and leisure activities, socialization. Placement could be state wide, rural setting.



B. PROGRAMS: Day activities program providing developmental skills training, gross motor, fine motor, pre-voc. The program must be flexible and able to deal with behavior problems.

C. SUPPORTIVE SERVICES: Medical services to check Tegretol levels (blood work every 3 months); review medication every 2 months; mental health services to develop and monitor behavior management programs; P.T. consult to evaluate range of motion.

D: COMMENTS:
There are no facilities available or on the horiz[illegible] which offer the degree of supervision or type of training which N needs.

E. BARRIERS: Lack of facilities serving profoundly retarded adults with behavior problems. N 's low tolerance for structured activities and his unacceptable habits.

F. TIME FRAME: REVIEW, PLACEMENT: Placement opportunities will be reviewed at each quarterly review.

DISCUSSION: N has not changed very much over the last year. He still presents some behavior problems in the form of stubbornness, aggression and unacceptable habits. The team agreed that sending N to his room to calm down is effective in decellerating behavior and should continue to be used. The cause of his outbursts are unknown as the circumstances vary. The general impression of the team is that N 's nature tends to be moody and he does not know how to appropriately release tension. In discussing programmatic goals for the next year it was noted that N shows no inclination towards any specific areas (vocational vs activity type of program). He does have an obvious preference for walks and outdoor activities. It was decided that this team would make recommendations to the Behavior Intervention Program to improve attending skills in fine motor and pre-vocational tasks, develop a cooperative attitude towards staff in following directions, and improve social behaviors by teaching N to use a handkerchief rather than "snort" on his hands. Active range of motion should be provided through gross motor activities. In the area of ADL skills N needs to refine eating skills, slowing down and to learn not to shake his cup or glass after it is empty. He should continue to receive training in face and hands washing as well as oral hygiene.

He should continue to attend community trips of a recreational nature, but is not ready to shop or eat in the community.

N 's primary aide reported that N does not like to be told what to do and that he

R L - IDT: 5/19/80

COMMUNITY PLACEMENT ANALYSIS

A. RESIDENCE: TYPE, LOCATION, LEVEL OF SUPERVISION:

R needs a small 6-8 bed group home in or around Region 5. Structure should be designed as to allow consistency and carry-over in A.D.L. skills, home life skills, as well as offer R a variety of recreational leisure time activities and community exposure.

B. PROGRAMS: R could best benefit from a developmentally appropriate day activities program which could offer him a variety of Fine & Gross Motor activities as well as recreational activity and community exposure.

C. SUPPORTIVE SERVICES:

D. COMMENTS:

E. BARRIERS:

F. TIME FRAME: REVIEW, PLACEMENT:

Due to the lack of facilities in Region 5, placement is to be reviewed at R 's next annual IDT meeting.

DISCUSSION:

R is appropriately placed at Vosburgh Hall I with appropriate peers and programs offered him. His behavior in the building and program area is described as mischievous and he requires much supervision, which eliminates R having grounds privileges.

R is a very alert individual and responds to his environment. He is partially independent at ADL skills and the team recommends he be involved with home life skills program training for his structured leisure time.

COMMUNITY PLACEMENT ANALYSIS

RESIDENCE: TYPE, LOCATION, LEVEL OF SUPERVISION: A pediatric ICF/MR nursing in region V to maintain parental involvement. The home should be warm and nurturing, training in home life and self-care skills should be provided, and opportunities for recreational and social activities should be available. The staff ratio should be 1-4 in the daytime with close supervision.

PROGRAMS: A daily education/stimulation program with training in developmental and daily living skills. Carryover of recommendations from the support services should be included in that program.

SUPPORTIVE SERVICES: Occupational Therapy by an OT aide, Physical Therapy by a PT Aide with supervision from an OTR and an RPT respectively. Orthopedic followup and yearly psychological services would also be needed.

COMMENTS: H presents no major behavior problems and could reside in an ICF. The staff would need to continue with an intense program and provide stimulation activities to discourage the self-stimulatory behaviors.

BARRIERS: Lack of a facility.

TIME FRAME: REVIEW, PLACEMENT: As there is no facility available presently, the team will review placement by June 1981.

DISCUSSION: The team was in agreement that H , although she has not made significant skill gains in the past year, would benefit from continued training. Of particular concern to the team was H 's almost constant self-stimulatory behavior. The team felt that this behavior impacts on the ability to make gains. Occupational Therapy staff have offered numerous suggestions to reduce the self-stimulation which all staff should be aware of and utilize.

PRIVILEGED AND CONFIDENTIAL
NOT TO BE USED AGAINST
PATIENTS INTEREST.

PINELAND CENTER -3-

CASE NO. 3875 NAME: [redacted]

YEAR NO. 167 DOB 12/5/58

INTERDISCIPLINARY TEAM REPORT

STRENGTHS

-personable young lady

-no major behavior problems
-father and sister are her guardians
-[redacted] is healthy
-[redacted] does well with some personal hygiene activities

-enjoys and benefits from daily school program

NEEDS

-continued community and social events participation
-needs to learn leisure time activities
-maintain frequent contact with them

-continued recreational activities
-needs refinement training in most of these areas
-needs a smaller homelike living environment
-continues in that program utilizing the more precise methods of teaching
-introduce pre-vocational training
-continue disipline therapies as needed: feeding program, signing program

COMMUNITY PLACEMENT

1. Environment/Services
   -homelike nuturing environment
   -medical, psychological services
   -day program and transportation services

2. Location
   Region V is preferred

3. Type of Supervision
   2:6 staff to resident

4. Program
   -full day academic and pre-vocational program
   -access to recreational facilities
   -planning for leisure time activities
   -training in home care tasks (cooking, cleaning, etc.)
   -communication training (signing program)

5. Comments
   Though [redacted] is not functioning on a level correspondent with many previously placed higher functioning people, it should not be considered a deterrent to placement but serve as a signal to the state as a growing unmet need in our population.

PINELAND CENTER

CASE NO. 3874 NAME [redacted]

YEAR NO. 167 DOB 12/5/38

INTERDISCIPLINARY TEAM REPORT

IV COMMUNITY PLACEMENT (continued)

6. Time Frame for Placement
In her previous IDT it was set for 12 months. There are no existing or planned homes to my knowledge. I will therefore set a hopeful date of 12/83. Please see unmet needs section for interim action.

7. Barriers
There are no existing homes to meet [redacted]'s needs.

V CERTIFICATION

[redacted] was certified on 3/3/72 for admission to Pineland for a period of 24 months.

COMMUNITY PLACEMENT ANALYSIS

1. RESIDENCE: TYPE, LOCATION, LEVEL OF SUPERVISION:

The team recommends a small group home designed to serve adults with training needs in ADL skills, community survival, socialization. 24 hour coverage and a quiet and relaxed environment are essential.

Annual medical and dental check-ups.

2. PROGRAMS:
Day activities program providing training in developmental skills as well as therapeutic intervention in the form of sensory stimulation activities. Again, relaxed pace and quiet environment are essential.

3. SUPPORTIVE SERVICES:

Occupational therapy for development and monitoring of sensory stimulation program.

4. COMMENTS:

PRIVILEGED AND CONFIDENTIAL
NOT TO BE USED AGAINST
PATIENTS INTEREST.

5. BARRIERS:
Lack of facilities providing the services and level of care needed in terms of residence and program.

6. TIME FRAME: REVIEW, PLACEMENT:

Placement is not expected within the next year due to the lack of facilities.

DISCUSSION: S is reported to be doing well at KH 4 though she has not made easurable gains. The unit is quiet and provides the training that she needs in elf-care. There was some discussion of her toileting habits as she has been reported o be constantly wet. Staff have also reported very strong body odor. The nurse uggested that S should be seen at the clinic or a vaginal smear and urine culture hould be done to determine whether or not S has an infection.

here was no representative from the program present at the meeting. This coordinator greed to meet with staff from Open Classroom Plus to discuss S 's strengths and needs s they relate to the goals and activities provided by that program.

t was agreed that S should remain at KH 4 with training in all areas of ADL and emphasis n washing face and hands. She should participate in regular community trips and special vents at Pineland.

he team was asked to consider spending some of S 's money on a Mortuary Trust Fund. hat was approved. Clothing and personal needs are met, however it was recommended that might benefit from having her own rocking chair.

PINELAND CENTER

CASE NO. 3794 NAME L G

YEAR NO. 88

INTERDISCIPLINARY TEAM REPORT - 9/27/79 Page 2

III.

| Strengths | Needs |
|---|---|
| - capable of doing Activities of Daily Living tasks with supervision<br>- good general health<br>- doesn't present any major maladaptive behaviors<br>- good verbal skills - uses correct tenses, as well as plurals, pronouns and prepositions "in", "on," and "under "<br>- has parents who are interested in her future and well-being<br>- is presently active in full day of programs, Monday - Friday<br>- is usually alert, cooperative, and neat in appearance<br>- good attendance at current programs<br>- enjoys field trips and is generally well-behaved | - more training in areas of ADL specifically, bathing, use of breath and body deodorants, feminine protection, and using the bathroom<br>- education in practical areas: days of the week, time of day, months, seasons, mealtimes, holidays, etc.<br>- exposure to more community oriente experiences<br>- skill development in cane travel and other safety and mobility skills<br>- a program in the community geared for educating or training blind people<br>- more recreational skill develoment<br>- training in household chores - laundry, making her bed, organizing her closet and drawers |

IV. Community Placement

The IDT recommends that G be placed in a home designed for visually impaired. This would be the ideal placement. Otherwise, G could be placed in a home where staff were trained to work with visually impaired people. There would need to be an adequate client/staff ratio so that someone would be available to orient G to her surroundings and guide her through tasks.

G should continue to be involved with educational programs as she should learn as many skills as she can that will make her more independent. The team feels that she would benefit from prevocational training and eventually be able to work in a sheltered workshop or an adult rehabilitation program.

The team feels that G is ready for immediate placement and that there are no real barriers besides her visual impairment.

Certification Requirements - G was certified on Feb. 28, 1978 as eligible to remain at Pineland for 24 months.

Due to a change in Program Coordinators and the lapse in time between the IDT meeting and the writing of this report I have included all the information I have been able to gather. Should any questions arise concerning G L 's current program or community placement, please contact me.

Carol Himmelman

Carol Himmelman, Program Coordinator

CH/hc
1/14/80

# APPENDIX II

## RECOMMENDATIONS AGAINST PLACEMENT

COMMUNITY PLACEMENT CONSIDERATION

N E was not considered an appropriate candidate for community placement at this time. N still exhibits unpredictable behaviors at times (biting, kicking and digging himself or others). The team agreed N needed constant supervision, ADL training, programming, recreational activities and Community exposure of which he is getting here at Pineland. Community placement will again be discussed at his next annual IDT 8/20/80.

CERTIFICATION CONSIDERATION P.L. 502

N E was certified through District Court on 2/21/78 for a period not to exceed 24 months. This team recommends a recertification of 24 months.

PINELAND CENTER

CASE NO. 2908 NAME J A

YEAR NO. 2 DOB: 12/22/38

INTERDISCIPLINARY TEAM REPORT Page 2

COMMUNITY PLACEMENT CONSIDERATION

In order to obtain an appropriate placement for A his present behavioral outburst of striking out at both staff and peers and ripping clothing would have to be more under control. He has made slight progress over the past year but still needs assistance in ADL, an activity program (i.e. ADAC) Communication therapy (signing) and recreational activities of which Pineland is providing to him. Community placement will again be discussed again on or before 9/10/80.

CERTIFICATION CONSIDERATION P.L. 502

A was recertified through District Court on 2/13/79 for a period not exceed 24 mos.

CASE NO. 3122 NAME H K

YEAR NO. 21

INTERDISCIPLINARY TEAM REPORT - 7/26/79 Page 2

Building Report: Prepared by Kim Chamard, MHWI

K H is a 36 year old male in KH 4. He is a verbal resident. K will repeat phrases or words heard from residents or staff. K is self-abusive; when upset, he will slap his face, bang his head, scream and hit others. Most of K 's time is spent in the day hall sitting in a chair twitching and picking his fingers to the point where they may become infected. He also scratches his leg (left).

K is very good in his ADL skills. He dresses himself. He buttons and snaps his clothes.

Certification Consideration

K is a profoundly retarded individual who requires treatment of an intensive nature. Pineland is the only, the least restrictive, and the most appropriate treatment site available to K at this time. K is unable to voluntarily participate in the admissions process.

Community Placement

Since K has been at Pineland for the last 22 years, except for a brief trial in a boarding home on 5/78 which ended when K became increasingly upset and destructive, this Interdisciplinary Team recommends a transfer to a higher functioning unit such as Staples Hall or Cumberland Hall to give K the opportunity to experience a change and a chance to live in a different physical environment with residents who are closer to his level of functioning. Once transfer has been accomplished and K has a chance to adjust to this change, and once this IDT reviews his progress, community placement will once again be reconsidered.

COMMUNITY PLACEMENT ANALYSIS

A. RESIDENCE: TYPE, LOCATION, LEVEL OF SUPERVISION:

ICF-MR or ICF-Geriatric in the Pownal to Farminton area with supervision available around-the-clock.

B. PROGRAMS:

A.D.L. maintenance efforts, mild leisure time activities, social opportunities, community excursions, rides.

C. SUPPORTIVE SERVICES: Medical/Nursing; transportation, provisions for recreation leisure activity, friendly, interested staff and peers for conversation, walks, etc.

D: COMMENTS:

The team prefers C remain at Pineland. See Discussion.

E. BARRIERS:
C probably would not be acceptable to a nursing home because of the amount of supervision needed to allow him freedom of movement.

F. TIME FRAME: REVIEW, PLACEMENT:
Review as usual through the IDT process or immediately if an unusually good alternative for C became available.

DISCUSSION: The team reviewed C 's program at Pineland and continued it as is but with some more emphasis on community exposure and experiences.

The need for information sharing between PHHII and CHI staff when C transfers was reinforced.
The possibility of placing C out of Pineland was discussed. This was decided against for two reasons. First, C functions well at Pineland based on the familiarity from fifty-three years of residence. It would be to his disadvantage to upset this familiarity. Secondly, a nursing home could very likely be more restrictive for him in Medical and Program services, opportunities for Recreation and in simple freedom of movement. Additionally, it was felt that C wouldn't be a desirable candidate from the nursing home's point of view because he needs to be watched a lot and his minor problems (wetting in the corner, consuming cigarette butts, "stubborn" nature) would probably be considered major problems.

PINELAND CENTER

CASE NO. 1995 NAME K D

YEAR NO. 32 D.O.B. 8/6/32

INTERDISCIPLINARY TEAM REPORT Page 2

II. SYNTHESIS OF IDT REPORTS (Cont.)

In Communication, D is scheduled for 3 times/week, either individually or with 1 other resident. She holds or mouths offered toys. She eyetracks toys moved in front of her to some extent. She can follow the direction "come here," provided she is in a good humor. She uses no words or jargon, and does not babble, but she screams, whines or cries when upset. D seems to enjoy following aides in a teasing manner, and will follow other residents to take their toys away.

Gross motor activity is D 's most advanced dimension of functioning (3.23 years), with Communication least developed at less than one year. For about a year, D has been the recipient of special attention and programming from Psychology. Previously she had slept in a crib surrounded by a net, now she sleeps in a regular bed. A vest bed restraint program has recently been started once again, as her night time behaviors have again become disruptive. Once again also, she has become aggressive to others by scratching and digging. She is profoundly mentally retarded, SMA of 1.65 years, SMQ around 7.

III.

| STRENGTHS | NEEDS |
|---|---|
| -independent in mobility, but unsteady | |
| -likes to "dance" with staff | -does not like physical assistance (but needs help with toileting, eating) |
| -likes attention from staff | -more independent abilities |
| -eats by herself with spoon, but messily | -elimination of mouthing behavior with toys and shirts |
| -will assist in dressing (holds out arms and legs) | -establish appropriate sleeping patterns |
| -can distinguish favorite staff | |
| -has a guardian who displays some interest in her | |



IV. COMMUNITY PLACEMENT CONSIDERATIONS

D 's present behavior (withdrawal from residents and staff, and conversely aggression against them by means of hitting, biting and uncooperativeness), and her disturbed sleeping patterns make her a most unlikely candidate for community placement. If she could be placed, it should be in an ICF-MR which could provide her with plenty of attention, continued ADL training, and programming similar to what she receives in the Open Classroom (O.T. type activities, Education, Recreation and Communication. She also has trouble with stairs, which combined with her unsteadiness, would necessitate a single-floor living arrangement.

PINELAND CENTER

CASE NO. 2865 NAME Y A

YEAR NO. 108 D.O.B.: 3/ 7/27

INTERDISCIPLINARY TEAM REPORT - (Continuation of 10/18/79 IDT)

I. Resident Name: A Y Residence: Cumberland Hall I

Team Members Present: Sandra White, MRCW
Robert Anderson, MHWII
Beverly Paige, Psychologist
Peter Reynolds, Dir., NGLC
Brooke McReynolds, R.N.
Kathy Garsoe, OTA
Rick Deeves, Recreation student
Aileen Stasulis, Program Coordinator

Date of IDT: 3/11/80 Report Written by: Aileen Stasulis
Title: Program Coordinator
Date of last IDT: Date Written: 3/17/80

Certification Date: 3/13/80 Length: 15 months Expiration Date: 6/13/81

Guardian: Bureau of Mental Retardation

II. Discussion

A 's Interdisciplinary Team met on this date to revise and update the IDT of last October. At that meeting, a rather significant drop in A 's functioning particularly in hearing and vision had occurred. Since A was scheduled for cataract surgery on Oct. 25, much of the discussion and most recommendations were deferred pending results of the surgery.

A has made a satisfactory recovery from the surgery with his vision having greatly improved. His vision now appears to be adequate for general mobility purposes although the IDT requested that his actual visual capacity be assessed if possible.

The team explored various programs and services to meet A 's fairly complex needs. He attended the New Gloucester Program but was dropped because he was not benefitting from any aspect of the program and seemed to be resisting the classroom structure. A was identified as a priority candidate for the geriatric program when a vacancy arises. Until that time, A will be given a trial at the pool with the geriatric group and involved in as many activities as possible with the C.H. I residents. A recreation student will also be working with A to try and find some activities that he enjoys. Lastly, the team recommended that Mary Crichton be notified of A 's specialized needs which should be considered in future program development.

III. Community Placement

1. Environment/services - a small group home with a considerable amount of supervision in view of his wandering and searching for cigarette butts

PINELAND CENTER

CASE NO. 2865 NAME Y A

YEAR NO. 108

INTERDISCIPLINARY TEAM REPORT - Continuation of 10/18/79 IDT 

Community Placement (Cont'd)

2. Location - A mother and half-sister live in Winslow, Me. and the ideal placement would be in Region V; however, A could be placed statewide if an appropriate placement arose.

3. Type of supervision (see Environement/Services)

4. Programs - the home should be designed for older residents who are not able to tolerate a full day of formal programming. In-house activities (walks, arts and crafts, etc.) and frequent community excursions would be an important aspect of a program for A ADL training would need to be continued with the emphasis on refining and improving his skills and increasing his independence in all areas.

5. Comments (refer to Environment/Services, Program).

6. Time frame for placement - the team does not see community placement as a realistic alternative for A within the next year. The situation will be reassessed and reevaluated by the team at A next meeting.

7. Barriers - a major barrier to A being readily and appropriately placed in the community is A inability to tolerate formalized programming. A needs a home where outside programming is not mandatory and where he can participate in leisure, preferably in-house, activities.

A also has an affinity for cigarette butts and must be supervised as he has gotten lost when he's been outside searching for them. In general, A resists and avoids social interaction which does not make him a desirable candidate for most community homes.

Recommendations of the IDT report dated 5/22/78

1. P is to remain residing at Doris Sidwell Hall maintaining current ADL programs under the supervision of John Knowles.

   Status: P resides at Sebago House with current ADL skills of bathing and proper care of his partial plate. P now shows his partial plate to the staff to make sure it is clean.

2. P is to continue his Experiences of Daily Living classes with goals as described in the full report. Mary Turner, Instructor, is responsible for this programming.

   Status: P remains with Mary Turner as Instructor in his EDL class with goals as outlined in accompanying report.

3. P is to continue with the Work Activities Center with a time change from 2:30 to 4:00 p.m., Monday - Thursday. Dave Littlefield, Adm. Asst. Activities and Training, is responsible for this programming.

   Status: The time change has been implemented and is working. P needs time to sleep or rest after lunch.

4. Sandra White, PASW, is responsible to pursue an appropriate placement for P Until such time that a placement can be located he is to remain residing at Doris Sidwell Hall.

   Status: There are no placements so far that have been developed or are in the process of being developed that are appropriate for P needs. Therefore, P remains residing at Sebago House with former Doris Sidwell Hall grouping.

Community Placement Considerations

Due to P previous placement, this Interdisciplinary Team recommends a gradual exposure to community surroundings and activities. A first step toward this goal is to recommend P to the Freeport Workshop when it opens August 15 of this year. It is also recommended that once an appropriate community placement is found, that P have regular access to a mental health facility.

Guardianship

Guardianship is still pending.



Certification

On October 31, 1978, P was certified to remain eligible for admission to Pineland Center for a period not to exceed 12 months.

PINELAND CENTER

CASE NO. 2707 NAME J A

YEAR NO. 27

INTERDISCIPLINARY TEAM REPORT Page 2

VII. STRENGTHS

He has a concerned and interested father.

He can communicate discomfort. He can smile and laugh

He can anticipate some things (as in associating sound of crib bed closing with staff person leaving the area)

He can hug an aide and tolerate being embraced for about a minute. He can cooperate in ADL to some extent.

He can walk with help for short distances.

He recognizes familiar staff.

He is calmed by use of a vibrator/ warmer

He likes to eat, to sit or lie quietly, and to be left unbothered

He has concerned and involved primary aides and teacher. Staff have a variety of other staff available for consultation.

NEEDS

To be "handled with care"

To be walked on unit

To vary position and posture

A non pressured daily life. Light and limited activity on unit

Sameness of environment and routine

Sameness of staff, consistency of approach



VII. COMMUNITY PLACEMENT CONSIDERATIONS

As a very long range objective, A would need an ICF/MR in Region 3 with medical/nursing services and consultive P.T., O.T., and Psychology services.

The environment should maximize sameness of surroundings, routine, and primary aides and should be non hectic.

A has little tolerance for change, due to multiple handicaps, and definite adjustment/transition problems would be expected if alternate placement were made (re: visual impairment and self injurious behavior). Alternate placement should be avoided, if possible, for the present.

PINELAND CENTER

CASE NO. 1098 NAME M J

YEAR NO. 6 D.O.B. 11/14/01

INTERDISCIPLINARY TEAM REPORT

I Resident Name: J M Residence: Perry Hayden Hall I

Team Members Present: H. Jay Monroe, Ph.D. (Psychology); Frank Rollins, ACSW, LCSW; Ciro Russo, Program Coordinator.

Team Members Absent: Residential, Nursing, Physical Therapy.

Date of IDT: 4/15/80 Report Written by: Ciro Russo
Title: Program Coordinator

Date of Last IDT: 5/8/79 Date Written: 4/16/80

Certification Date: 9/26/78 Length: 24 months Expiration Date: 9/26/80

Guardian: Mrs. Vachon

Reports Attached: Social Service, Medical, Communication, Psychology, Building.

II COMMUNITY PLACEMENT CONSIDERATIONS

J would need an ICF or ICF-MR to meet her medical and nursing care needs if alternate placement were to be sought.

J is difficult to care for but is successfully being cared for in her present home.

The Team recommends she remain in Perry Hayden Hall I because the staff there are doing so well with her and moving to an alternate placement may jeopardize the stability of her fragile health. Also, no less restrictive environment is known of and moving J would not be purposeful.

III ADMISSION CERTIFICATION CONSIDERATIONS

In accordance with P.L. 502 this Interdisciplinary Team has made the following determinations concerning J M 's admission to Pineland Center:

1. that J is mentally retarded.
2. that J requires care of an intensive nature.
3. that Pineland is the most appropriate and least restrictive treatment site for J .
4. that Pineland has available the services J needs.
5. that J is not capable of voluntarily participating in the admission process.
6. that twenty four months certification is called for.

IV DISCUSSION

J 's family and guardianship situation was reviewed and it was pointed out that Mrs. V is concerned that J not be caused discomfort by medical testing or exams.

PINELAND CENTER

CASE NO. 1098 NAME M J

YEAR NO. 6 D.O.B. 11/14/01

INTERDISCIPLINARY TEAM REPORT Page 2

IV DISCUSSION (Cont.)

The consensus of discussion of placement was that the Perry Hayden I staff are doing an excellent job with J ; that alternate placement would most probably endanger her fragile health (for example, she has been progressively losing weight); and that an alternate placement would not be less restrictive, i.e. her situation is normal for her status.

Other considerations pointed out were: she has funds in her account if she needs any purchases made; the amount of her Mortuary Trust fund is relatively small (so, the amount in her account will be monitored in case additional funds are needed for mortuary expenses); J has some wakeful nights but changes in discrimination of night and day occur at her age and physical status; J should not be required to attend major recreational events, eat in a public place monthly, attend formal, structured, activity programs, etc.

UNITED STATES DISTRICT COURT

DISTRICT OF MAINE

| | | |
|---|---|---|
| MARITTI WUORI, et al., | ) | |
| | ) | |
| Plaintiffs | ) | |
| | ) | |
| v. | ) | CIVIL NO. 75-80-P |
| | ) | |
| KEVIN CONCANNON, et als., | ) | |
| | ) | |
| Defendants | ) | |

STIPULATION AGREEMENT

INTRODUCTION

With respect to the continuation and modification of the office of the Special Master as set forth in this Court's order dated January 14, 1981, the parties enter into the following stipulation agreement.

This stipulation agreement contains a description of the major accomplishments of the defendants under the terms of the Consent Decree; a description of areas where defendants have not achieved compliance with the terms of the Consent Decree; a description of the corrective action defendants agree to undertake in order to achieve compliance in the areas described; and a description of the procedures to be employed by all persons concerned with the enforcement of the Consent Decree in carrying out the terms of this agreement.

This stipulation agreement does not supercede the terms of the Consent Decree entered into by the parties and approved by the Court on July 14, 1978, the terms of which Consent Decree remain in full force and effect.

Furthermore, the parties commend herewith Special Master David Gregory for his steadfast insistence on the implementation of the Consent Decree according to its terms. Through his office he has assisted the defendants in taking concrete steps toward decree compliance. The lives of mentally retarded citizens of Maine will be substantially enhanced by his contributions.

I. ACCOMPLISHMENTS OF DEFENDANTS

A. Accomplishments of Pineland Center

1. Pineland Center is in substantial compliance with the provisions of the decree.

2. Pineland Center is providing programming and care necessary to give residents the opportunity to develop their abilities as identified in their individual prescriptive program plans. Medical and professional services are available to address the severe and complex biomedical, behavioral, and emotional needs of the residents at Pineland Center. Residents at Pineland are provided a safe, healthy environment, and are encouraged to develop their ability to cope with the world around them.

3. The population of Pineland Center has been reduced to 325 residents.

4. Residents are receiving six hours of programming per weekday unless otherwise medically excused from programming, newly admitted to Pineland, or at Pineland for respite purposes.

5. Day programming for residents at Pineland Center is provided by Berman School, the Adult Day Activity Center, the Geriatric Program, the Leisure Center, the Open Classroom, the Perry Hayden Hall Activity Center, the Learing Cooperative, Camp Tall Pines, the gymnasium, the pool and the workshop.

6. Professional services are provided by trained physical therapists, occupational therapists, nurses, physicians, communication specialists in speech and audiology, psychologists, recreational therapists, social workers and educators.

7. Staffing ratios called for by the decree are met throughout the institution for both professional and nonprofessional staff.

8. Each resident has had the benefit of an annual inter-disciplinary term review of his case, and has had an individual program plan prepared on his behalf to address his particular needs for developmental programming to achieve greater interdependence.

9. Programming is provided to each resident at his development level.

10. Respect for the rights of residents is fostered by Pineland's policies and procedures, by the resident advocate and by the Human Rights and Assurances Committee. No doors are locked at Pineland.

11. Residents' rights of privacy have been increasingly respected by installing doors or visual barriers on bedrooms and bathrooms, by providing residents individual storage space and by eliminating all of the large wards.

12. Throughout the institution the environment has been made more homelike and more pleasant for the individuals living there. To this end, units have been converted to apartments or small "homes", day room and dining halls have been broken down into smaller living or dining areas and new furnishings and decorations have been obtained.

13. Residents at Pineland are appropriately dressed throughout the year. Many residents participate in the selection of their own clothing.

14. A variety of recreational activities are available at Pineland and in the surrounding area throughout the year.

15. Provisions to increase th level of staff training include a university affiliated Associate Degree program in developmental disabilities, a medication course, a certified nurses aid course and a wide variety of in-service educational programs.

16. Fire and safety inspections are conducted on a regular basis and complaints are promptly investigated. Deficiencies are corrected or plans are made to correct them.

17. Specialized clinics for seizure control, for orthopedic and dental treatment, and for chromosome analysis and genetic counselling are available for residents and out-patients.

18. The use of psychotropic medications has been reduced by increasing resident programming, by close monitoring, and by regular implementation of drug holidays.

19. Staff morale has been greatly increased such that most staff members can be observed working directly with the residents to whom they are assigned.

B. Bureau of Mental Retardation Accomplishments Under Appendix "B" of the Consent Decree

1. Defendants have designed an individual programming system which is capable of assessing needs and designing programs for clients based on those needs.

2. Defendants have developed program plans for each member of the class.

3. Defendants have exceeded the requirements of Appendix B, Sec. C.8.a. and b. of the decree for the development of new residential placements during the first two years of the decree. A number of homes have been developed to serve clients with needs requiring specialized services, such as those for individuals with dual diagnoses.

4. The Maine Legislature appropriated the following sums to the Bureau of Mental Retardation for the development and continuation of community programs for the mentally retarded citizens of Maine:

For Fiscal Year 1979. . . . . $1,413,427

For Fiscal Year 1980. . . . . $2,386,578

For Fiscal Year 1981. . . . . $2,348,083

5. In cooperation with the Bureau of Rehabilitation of the Maine Department of Human Services defendants secured additional funding for vocational programs for the mentally retarded in the following amounts:

For Fiscal Year 1980. . . . . $132,912

For Fiscal Year 1981. . . . . $181,012

6. Defendants have spearheaded the development of the ICF/MR program in Maine. Initially, 21 homes, representing 136 residential placements are scheduled to commence providing services under this program in the current fiscal year. It is anticipated that these homes will provide enhanced programming for their residents at an annual cost of approximately $3.5 million, of which nearly 70% is federally reimbursable.

7. In conjunction with the Bureaus of Rehabilitation and Resources Dvelopment of the Maine Department of Human Services defendants have developed standards for assessing the quality of adult community day programs serving the mentally retarded.

8. Defendants have established and staffed two resource centers for the provision of professional evaluative services in the fields of psychology, occupational therapy, physical therapy and speech therapy.

9. Defendants have delivered training relative to several major areas in the Decree, including habilitation plan development, client rights, client goal setting, and behavior analysis.

10. Except in Region I, defendants have hired resource development staff required by the terms of the decree.

11. Defendants have published 3 annual issues of a director of resources and services available in the community to mentally retarded persons.

12. Defendants have established a statewide system for maintaining client funds, including individual NOW accounts for each client for whom the Bureau of Mental Retardation is guardian or representative payee.

13. Defendants have retained professional consultants to assist in the implementation of the Consent Decree.

14. Defendants have upgraded the qualifications, responsibilities and salaries of regional staff in order to recruit qualified persons to work on behalf of the mentally retarded citizens of Maine.

II. LIST OF DEFICIENCIES

1. In each region of the State, large or programmatically inadequate homes continue to provide residential services to clients.

2. Programming in the community does not fully meet Decree standards, in part due to deficiencies in the Individual Program Planning process. Recommendations are not consistently based on the needs of clients, measurable goals and objectives are not consistently defined, and program monitoring is not carried out in a reliable manner.

3. There remain gaps in providng a continuum of residential and program services. These gaps are especially apparent for clients ready for more independent employment and residential opportunities, and for clients who are multiple handicapped or who present behavior problems.

4. While professional evaluation services are generally available, recommended professional treatment, especially in the area of physical therapy and occupational therapy, psychology and speech and hearing (communication), cannot be carried out in many cases. In addition, professionals are underutilized in the IDT/IPP process.

5. Gaps continue to exist throughout the community system in the following areas: transportation, crisis intervention, family support, respite services, and in provisions for community recreational opportunities.

6. Systems to track client needs, to plan for resource development, and to monitor actual service delivery are not adequate to assure quality services or to assure the coordinated development of services to meet client needs.

7. A comprehensive and coordinated training program in not uniformly accessible, and particularly for service providers, is inadequate.

8. Community placement needs of Pineland Center residents are not identified or complied in a manner conforming to Sections D.5 and 11 of Appendix A in that Prescriptive Program Plans do not contain the date for progress to a community

setting, and the interim plans of Pineland Center residents do not contain projected dates for community placements. As a consequence, community resources development planning does not adequately address the community placement needs of Pineland Center residents.

III. PLANS OF CORRECTION

1. Within six months of the date of this agreement, all clients shall, in conformity with provisions of Appendix B, be removed from the following residential placements: Seven Elms Boarding Home, Willowcrest Boarding Home, and Hilltop Boarding Home.

2. Within two months of the date of this agreement an expert shall evaluate the residential and program services provided at the following residential placements: Ward's Home, Pinkham's Home, and Northland Manor. On the basis of evaluation, and within one month thereafter, defendants shall either determine that all clients be removed from these homes within six months in conformity with provisions of Appendix B or formulate a plan within two months which shall meet the substantive provisions of Paragraph 3 below.

3. Within three months of the date of this agreement, a comprehensive plan shall be prepared to reduce the population and/or increase the level of active programming at the following residential placements, and a specific agreement shall be entered with each placement operator to assure implementation of the plan: Bruce Haven, Tissue Boarding Home, Hall-Dale Manor, Noyes Boarding Home, and Houlton Residential Center.

4. Within one month of the date of this agreement, the Bureau shall initiate an individual case review to determine which clients living in nursing homes serving a preponderance of non-mentally retarded clients should be moved to more appropriate

settings to accommodate their specific programming and residential needs. For clients not recommended for movement, a professional team (PT, OT, Nursing, etc.) shall conduct on-site reviews to determine any additional needs of these clients for programming services or for alternative residential placements. These reviews shall be completed within three months. At the conclusion of these reviews, the parties shall meet to discuss the findings and to recommend the necessary elements of a plan to meet client needs. Within one month following this meeting, defendants shall formulate a plan to meet the identified needs of clients under this paragraph. Any client movement will be conducted within the provisions of Appendix B.

5. Defendants shall employ the results of their case record review to re-examine and, where necessary, restructure the Prescriptive Program Planning process. Specific attention shall be paid to the areas of client needs assessment, short and long range goal planning, staff and provider training, and PPP monitoring. Defendants shall engage the services of consultant experts, as necessary, to address specific elements of the PPP system. Changes to the amended Prescriptive Program Planning process and resultant changes to manuals, shall be completed and implemented within 5 months of the date of this agreement.

6. As soon as practicable after the completion of the task outlined in Paragraph 5 defendants shall evaluate a statistically significant random sample of those PPPs prepared under the revised PPP process to determine the impact of those revisions and make subsequent revisions two months after the completion of the evaluation.

7. The defendants shall assist the Consumer Advisory Board in making trained correspondents available for participation in the IDT meetings of all clients who are not able to advocate on their own behalf. Within two months of the date of this agreement, defendants shall make significant contacts with

special education and social welfare departments at colleges throughout the State to determine sound methods for obtaining correspondents and for providing them proper training. Within two months thereafter defendants, in conjunction with the Consumer Advisory Board, shall formulate a plan to achieve the goal of this paragraph.

8. Within three months of the date of this agreement, defendants shall retain a consultant in vocational programming to evaluate, relative to Decree compliance, the programs serving clients in the following agencies: Bangor Regional Rehabilitation Center, Goodwill, Coastal Workshop, Pathways, Winthrop Work Activity Center and Green Valley. The expert shall pay particular attention to the needs of clients to earn more money. Within two months thereafter defendants shall formulate plans to bring those programs into compliance with the decree.

9. Within one month of the date of this agreement, defendants shall develop an instrument to identify unmet residential and programmatic client needs, by type and location. A program type will be defined in terms of the categories of programs included in the State of Maine Inter-Agency Adult Community Program Standards. Residences may be defined as types comprehended by licensing regulations, but shall, where applicable, include reference to specific specialized services or environments necessary to meet client needs such as a signing or barrier free environment, mental health or behavioral management services, etc. In addition the instrument shall be designed to identify clients who are who can be assisted to become ready for independent or semi-independent living within one year.

Within three months of the development of the measuring instrument, defendants shall conclude a client review, utilizing the instrument, and shall compile the information obtained. An expert shall be retained who shall, on the basis of this information, and within one month thereafter, make recommendations as to the types

and locations of program and residential services which need to be developed to meet client needs. The expert shall give consideration to, and make recommendations as to the need for, the design of programs to permit clients to receive services within a multiple of types of programs, as their needs dictate. Defendants shall thereupon and within six weeks, develop a plan for the development and/or realignment of needed residential and program services to meet the needs identified by the review.

A specific section of the plan shall include a variety of strategies and methods for developing independent and semi-independent living arrangements. This portion of the plan shall be reviewed within six months, and the process to identify and plan for clients then ready for more independent living shall be reinitiated.

10. Defendants shall identify one person in each of the disciplines of psychology, occupational therapy, physical therapy and speech therapy, who will serve as liaison with their respective state and national organizations relative to the recruitment, development and utilization of professional resources, and the delivery of those services to members of the class. These representatives shall develop a plan of action within three months of the date of this agreement. Said professional shall meet on at least a quarterly basis with each of the regional offices. At these meetings the professionals shall collect all information relative to lack of services in their respective disciplines, and plan to correct those deficiencies. Defendants shall assign a person to coordinate the efforts of these professionals and to collect their reports and plans on a quarterly basis.

11. On a quarterly basis defendants shall report in narrative form all problems and progress toward the alleviation of deficiencies in the following areas: transportation, crisis intervention, family support, respite services, and community recreational opportunity.

12. Within three months of the date of this agreement, defendants shall thoroughly review their current systems to collect data, to track clients' needs, and to plan for resource development. On the basis of this review, and within one month thereafter, defendants shall formulate a plan to implement revisions in the design and use of these systems.

13. Defendants shall retain the services of an expert who shall review the monitoring systems of the defendants; and make recommendations to replace, revise, or supplement any standards, regulations, policies, practices or procedures relative to those monitoring systems to assure that defendants have a system which thoroughly evaluates services delivered to clients, assures the quality of those services, and provides the prompt correction of deficiencies when identified. On the basis of the expert's review and recommendations, defendants shall write a plan providing for implementation of necessary changes in their monitoring system. The plan shall be completed withix six months of the date of this agreement.

14. Within four months of the date of this agreement, defendants shall formulate a plan to provide Decree-compliant training for all employees and service providers to assist them in meeting Decree standards and to assist them in effectuating the purposes of Part III of this agreement. Said plan shall incorporate a variety of strategies and mechanisms designed to overcome present barriers to full training of service providers.

15. Pineland Center shall re-establish its Planning Committee to review each current resident's program plan respecting the analysis of a community placement best suited to the resident's progress toward community placement shall be assigned as precisely as possible, compiled and forwarded to the Bureau of Mental Retardation for consideration in the preparation of the long term community resource development plan discussed below.

Thereafter, IDT analyses of community placements best suited to each resident's needs shall include projected dates for the resident's progress to a community setting as required by Section D.5, Appendix A. Annual IDT reviews shall address the client's progress toward community placement. If a resident is determined ready for community placement, but the program is unavailable, defendants shall prepare interim plans pursuant to Section D.11 of Appendix A. If a resident is not recommended for community placement at the time of the IDT, the community placement analysis and projected date of progress to a community setting shall be submitted to the Central Office of the Bureau of Mental Retardation. Information provided in these latter instances, in conjunction with any similar data generated in the community, shall be used in the preparation of a long term resource development plan, to be prepared within six months of the date of this agreement, and to be revised annually thereafter.

IV. PROCEDURES

1. Whenever a plan is called for under this agreement, it shall include a description of the corrective action to be taken; a timetable for implementation of the action; a detailed description of actions to be taken on an ongoing basis to assure future compliance with the Decree in the area addressed by the plan; a detailed description of the means of obtaining the data necessary both to the writing of the plan and to the implementation of ongoing actions to assure future Decree compliance; a description of the source or sources of funding to be used in financing both corrective and ongoing actions; a description of any training necessary to the implementation of corrective action and ongoing actions to assure Decree compliance.

2. Where provisions of this agreement require the use of experts prior to the preparation of a plan, the selection of those experts shall be by agreement of the parties. Where agreement cannot be reached, selections shall be by the Special Master, after consultation with the parties. The parties and the Special Master shall be afforded the opportunity to meet with the experts before they commence performing services pursuant to this agreement.

3. Once a plan is completed, the Special Master, the parties, and any experts who participated preliminarily in the preparation of the plan, if their attendance is desirable and can reasonably be obtained, shall meet to comment on the plan; to review or establish timetables for implementation of the actions anticipated by the plan; to determine the means of evaluating the extent of compliance with the Decree in the area addressed by the specific plan; to select compliance reviewing experts, if it is determined that an expert shall conduct the Decree compliance evaluation. Where the parties are unable to agree on the above matters, the Special Master shall decide those issues.

4. Upon expiration of the deadline established for implementation of each plan, the parties, the Special Master and any expert selected to review compliance, shall meet to establish an agenda for evaluating Decree compliance. The agenda shall allow for expeditious yet thorough completion of the evaluation. The individual conducting the evaluation shall prepare a report for submission to all persons concerned with the enforcement of the Decree who shall have 30 days to file with the Master written comments. Thereafter, within seven days, the Master shall file this report, the relevant plan of correction and any comments with the Court.

Dated: January 14, 1981.

/s/ Neville Woodruff
NEVILLE WOODRUFF
Attorney for Plaintiffs

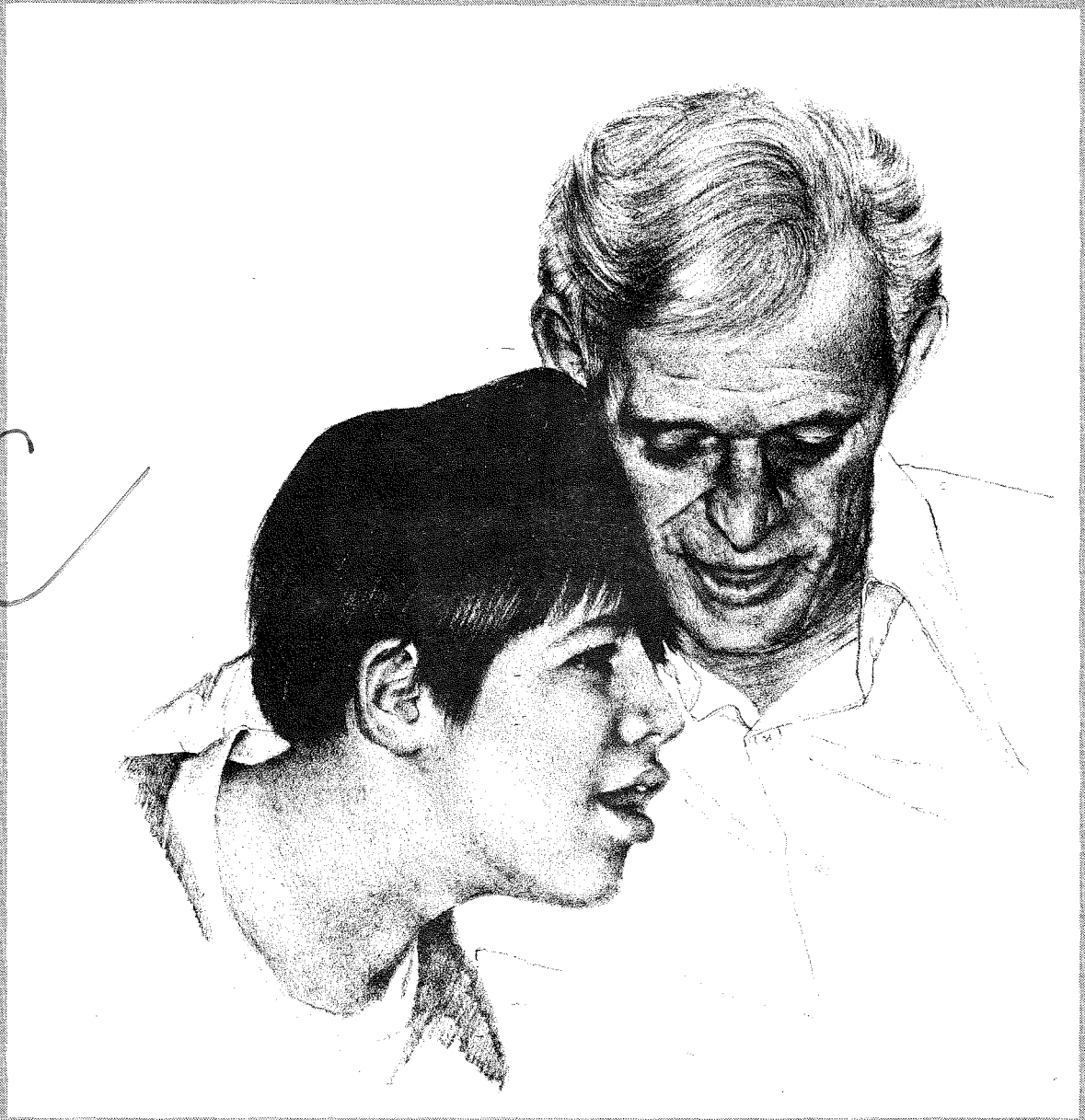
/s/ William C. Nugent
WILLIAM C. NUGENT
Assistant Attorney General
Attorney for Defendants

/a/ Helen Bailey
HELEN BAILEY
Attorney for Plaintiffs

/s/ William Laubenstein
WILLIAM LAUBENSTEIN
Assistant Attorney General
Attorney for Defendants

# THE MARTTI WUORI CASE

# REPORT TO THE COURT



## How Maine Cares For Its Retarded Citizens

United States District Court
Portland, Maine 04112

July 20, 1981

LINCOLN CLARK
SPECIAL MASTER

The Honorable Edward T. Gignoux
United States District Court
Portland, Maine 04102

Re: MARTTI WUORI, et al., Plaintiffs
v.
KEVIN CONCANNON, et al., Defendants

Dear Judge Gignoux:

Your "Order Continuing Office of Special Master" of January 14, 1981, requires that the progress, suggestions, recommendations and unresolved problems relating to compliance with the Consent Decree of July 21, 1978, and the Stipulation Agreement of January 14, 1981, be reported to the Court every six months, and that a preliminary draft be submitted to and discussed with the parties. The final discussion with parties and counsel took place on July 20, 1981.

The parties concur with the finding that Pineland Center is so fully in compliance with the Consent Decree as to merit the recommendation that the Court proceed to discharge Pineland Center from its jurisdiction. After being discharged, Pineland Center cannot disregard the Consent Decree but must continue to comply with its provisions and will collect and incorporate data relating to them in its Management Information System. The Bureau of Mental Retardation will include Pineland Center in the overall monitoring system that it is developing pursuant to Plans of Correction (12), (13) and (15) of the Stipulation Agreement and will continue to integrate the operations of Pineland Center into the State's system for the mentally retarded.

The parties are vigorously endeavoring to achieve compliance with the provisions of the Consent Decree relating to community services by the target date, July 1, 1982.

Also, it is suggested that there are inconsistencies between the provisions of the Consent Decree and the program regulations, principles and practices governing the Intermediate Care Facilities for the Mentally Retarded which the State should rectify in the consultation with the persons concerned with the enforcement of the Consent Decree.

Reaching compliance at Pineland Center is a splendid achievement for which the Court can applaud the parties. In addition, much credit is due the hundreds of staff and volunteers for their dedicated, rewarding, but under-rewarded service to Maine's mentally retarded citizens in over two hundred communities.

The parties concur with and accept the recommendations in this letter.

William H. Lawrence
Attorney for Defendants

Karen G. Kingsley
Attorney for Defendants

Attorney for Plaintiffs

Attorney for Plaintiffs

Respectfully submitted,

Lincoln Clark
Special Master

TABLE OF CONTENTS


| | | Page |
|---|---|---|
| I | INTRODUCTION | 5 |
| II | PINELAND CENTER | |
| | 1. Recommendation | 7 |
| | 2. Superintendent's Report | 7 |
| | 3. Auditor's Report | 15 |
| III | PLANS OF CORRECTION | 17 |
| IV | OBSERVATIONS | |
| | 1. Two-way Door Policy | 21 |
| | 2. Discrimination Between Classes of Clients | 21 |
| | 3. Communitization Policy | 22 |
| | 4. Grants to Parents | 23 |
| | 5. Encouragement of Independent Living | 23 |
| | 6. Establishment of H.O.M.E.S. | 23 |
| | 7. Support for Group and Boarding Homes | 24 |
| | 8. Revision of ICF/MR Regulations | 25 |
| | 9. Incentive Policy for Day Programs | 26 |
| | 10. Opportunities of Pineland Center | |
| | a. Training and Research | 27 |
| | b. Genetic Research and Counseling | 27 |
| | c. Cooperation with Colleges and Universities | 27 |
| | d. Certification Procedure | 27 |
| | e. "Maine Developmental Center" | 28 |
| APPENDICES | | |
| | . Personnel Requirements | A-2 |
| | . Habilitation after Communitization | A-6 |
| | . Distinction Between Types of DHS Regulations | A-10 |
| | . Incentive Policy for Day Programs | A-12 |
| | . DHS Disallowance of "Overtime" Labor Costs | A-20 |
| | . MR Offenders | A-23 |
| | . Financial Health of ICF/MRs | A-25 |
| | . More Pineland Placements to Foster Homes | A-31 |

# SECTION I INTRODUCTION

As a result of Martti Wuori, et al. v. State of Maine, a suit brought in Federal District Court on behalf of Pineland residents, the State of Maine entered into a Consent Decree on July 21, 1978. The principal purposes of that Decree were to improve conditions at Pineland Center and to provide for the "habilitation" and "communitization" of its clients.[1] To oversee implementation of the Decree, the Court appointed a Special Master, who submitted five reports to the Court: "Implications of the Consent Decree and Preliminary Observations on Implementation" (March 19, 1979); "Part I: Conclusions of the Special Master" and "Part II: Pineland Center" (November 14, 1979); "Community Standards: Appendix B of the Court's Decree" (April 22, 1980; "Continuing Supervision of the Decree," (June 2, 1981);and "Community Placement for Pineland Residents" (November 24, 1980).

The present Special Master was appointed on January 14, 1981, when the Court approved a Stipulation Agreement that supplemented, but did not supersede, the terms of the Decree. This Agreement described major accomplishments and deficiencies in complying to the Decree, and set forth corrective actions and procedures for improving compliance.

The Stipulation Agreement stated that "Pineland Center is in substantial compliance with the provisions of the Decree." In the six months since his appointment, the present Special Master has concentrated on encouraging further compliance-directed actions. Satisfying the Decree standards has from the beginning been a formidable task because of the manifold activities of Pineland Center, and because of differences in interpretation of provisions of the Decree, difficulties in determining the adequacy of various systems, and breakdowns in those systems. No organization functions perfectly day in and day out. Murphy's Law - "If anything can go wrong, it will" - operates inexorably. There will continue to be unwanted and unintended breakdowns in the complex organizational machinery of Pineland Center.

The systems of compliance are, however, now in place and operating efficiently, and provision has been made to assure that the standards in the Consent Decree will continue to be maintained. Pineland Center is now so fully in compliance with the Consent Decree as to merit a recommendation that the Court proceed to discharge Pineland Center from its jurisdiction. The bases for this recommendation are set forth in Section II of this report.

The Stipulation Agreement lists fifteen "Plans for Correction" for the remaining deficiencies. Some of these deficiencies have been corrected, in the past six months and the others are being corrected. Section III of this report details the progress.

In addition to Pineland Center, Maine has about 220 residential facilities and day programs for the mentally retarded. Each is expected to meet the standards of the Consent Decree as an integral unit of a smooth-working

---

1. These terms are professional jargon: "Habilitation" is the process of development of an individual's abilities to the maximum. "Communitization" is the process of progressive integration of an individual into a community.

statewide system. Additional community facilities are still needed to accommodate the many more Pineland clients who are qualified for community placement. Vigorous and persistent effort is required by the defendants to obtain the cooperation and support of State agencies, local communities, and parents of the members of the plaintiffs' class. Section IV of this report contains some observations aimed at speeding progress toward conformity with the terms of the Decree by the target date of July 14, 1982.

The Appendices contain memoranda from and to the Special Master, relating to some of the problems that have received attention during the past six months. It will be apparent that several of these problems remain to be resolved.

# SECTION II PINELAND CENTER

## 1. Recommendation

In the Stipulation Agreement of January 14, 1981, the parties acknowledged that "Pineland Center is in Substantial Compliance with the provisions of the Consent Decree." "Substantial" connotes considerable achievement, but it also implies that deficiencies remain to be corrected. This raised the question: at what stage of compliance would the Court dismiss Pineland Center from its jurisdiction? It is suggested that while full compliance is the ultimate goal, it should be sufficient for the Court to be satisfied that the "systems for compliance" instituted by Pineland Center offer promise of full compliance and that there be assurance that the systems would not deteriorate after Pineland Center is discharged by the Court.

During the past six months several meetings have been held with staff at Pineland Center regarding remaining deficiencies and the requirements for a recommendation to the Court. The result is the Superintendent's report which is contained in the following Sub-section. The report is supplemented by a mass of supporting data that has been filed with the Office of the Special Master.

So as to provide a double-check for the plaintiffs and the Court, an outside professional expert was retained to audit the Superintendent's report. His report is in Sub-section (3).

After a review, the parties and the Special Master, at their meeting on July 13, 1981, endorsed the following recommendation:

The parties concur with the finding that Pineland Center is so fully in compliance with the Consent Decree as to merit the recommendation that the Court proceed to discharge Pineland Center from its jurisdiction. After being discharged, Pineland Center cannot disregard the Consent Decree but must continue to comply with its provisions and will collect and incorporate data relating to them in its Management Information System. The Bureau of Mental Retardation will include Pineland Center in the overall monitoring system that it is developing pursuant to Plans of Correction (12), 13) and (15) of the Stipulation Agreement and will continue to integrate the operations of Pineland Center into the State's system for the mentally retarded.

## 2. Superintendent's Report

### INTRODUCTION

The action concerning the civil and constitutional rights of mentally retarded citizens of the State of Maine known as the "class action suit" was initiated by and on behalf of those persons who were involuntarily confined to Pineland Center, and persons conditionally released (placed) from Pineland Center to community facilities. A Consent Decree was entered into on July 14, 1978. This report concerns the compliance of Pineland Center with the provisions and standards as contained in Appendix A of the Consent Decree. The decree prescribes that it is to be interpreted "in a fair and reasonable manner so as to attain the object for which it was designed and the purpose to which it is applied."

## OBJECTIVES of the CONSENT DECREE

There are two major objectives of the Court's Decree: The first is to secure the right of mentally retarded citizens to be given training and education, in the Decree known as "programming." The second is the right to live in the least restrictive environment possible. These objectives mean that every resident of Pineland Center has the right to be taught whatever he may be capable of learning, with an emphasis on skills of daily living so as to increase personal independence and that residents at Pineland Center should live in as "normal" an environment as possible in the least restrictive setting. It also means that Pineland Center should prepare its residents for successful placement and participation in communities.

## METHODS to MONITOR COMPLIANCE

There are 315 individual standards contained in Appendix A of the Consent Decree. In order to implement and monitor the compliance with these complex and often confusing standards, Pineland Center undertook the task of collecting data and information on each standard through a reporting form developed by the Social Scientist at Pineland Center, Dr. John Hoffman. Some of these standards are monitored on a daily basis, most on a monthly basis, some on a quarterly or yearly basis.

In addition to the collection of data through the monitoring process described in this report, Pineland Center has undertaken an individual needs assessment of every resident living at Pineland Center. This needs assessment has been conducted twice. As a result of this assessment, a planning committee was established to implement the results. The major accomplishments of the planning committee were:

1) The relocation of all residents into smaller less restrictive, more "normal" residential units. (No resident lives in a bedroom area with more than two other roommates, most live in double rooms, some in a private room.) The size of the residential units has been reduced. Of twenty-five living units, one houses twenty residents, seven house eighteen residents, one houses sixteen residents, six house between thirteen and fifteen residents, three house twelve residents and seven house six residents.

2) An interface of professional and direct care staff resulting in more programming for the residents, more training for the staff and a better staff to client ratio so as to enhance the training and education opportunities of the residents.

3) The creation of specialized day programming for the elderly mentally retarded, the behaviorally disordered retarded person, and the creation of programming based on the needs of the client.

4) The development of new program areas to accommodate day programming. (Commons Building, Pownal Hall)

5) The closing of New Gloucester Hall, Pownal Hall as a residential unit, Sebago House as a residential unit, the closing of Perry Hayden III as a residential unit and the opening of the Federation Apartments as residential living units.

6) The reorganization of the Executive Management Committee and other departments at Pineland Center resulting in a more responsive organization structure.

7) The reorganization of the Interdisciplinary Team (IDT) process. The Interdisciplinary Team is the foundation for the development of the Individual Prescriptive Plan. It determines place of residence, treatment and program.

## ADDITIONAL REQUIREMENTS and REGULATIONS MET by PINELAND CENTER

In addition to the monitoring of Decree requirements and the implementation of the resident needs assessment, Pineland Center has met the educational, environmental, medical, health, safety and staffing requirements of the federal and state regulations (Title 19) of the Regulations Governing the Licensure of Intermediate Care Facilities for the Mentally Retarded. Pineland Center has been certified as an Intermediate Care Facility for the Mentally Retarded by a team of individuals representing the Division of Licensing and Certification, (nurses, sanitarian, social workers, dietician) and the State Fire Marshall. Through certification as an ICF/MR Pineland Center will return over six million dollars in federal monies to the State general fund.

## OBSTACLES to COMPLIANCE

It is important to recognize the context in which these accomplishments have been made. Pineland Center is an old facility. This in itself has required time, innovative techniques, money and expertise in order to transform the Center into a reasonable home-like, community-like environment for the residents. The census at Pineland Center has been reduced from an estimated fifteen hundred residents in 1955 to three hundred forty-four residents today. While the environment and census were being modified, staff was being added--from 660 in 1975 to 741 today. Professional level and direct care staff were recruited and trained to work with this special population.

As a result of the placement activity, the remaining residents and new admissions to Pineland Center represent a most severe and profound level of mental retardation. Today ninety-five percent of the population is severely and profoundly retarded as compared to a national average of approximately seventy-five percent. In addition, close to one hundred percent of the residents have multiple handicaps in addition to their mental retardation. Seventy percent of the residents do not have speech, forty-five percent are not able to dress themselves, forty percent of the residents are incontinent, sixty-five percent cannot clean and groom themselves even after repeated and continuing attempts at training in these fundamental skills. Over ninety residents are nonambulatory, and over one hundred have seizure disorders. There are forty-nine residents under the age of twenty-one living at Pineland Center.

In view of the severity of the handicapping conditions of the residents, further learning and achievement by the residents will be very slow. This is not to suggest that they won't continue to develop but that on a cognitive level progress will be minimal. This severity of mental retardation also means a population at risk with medical complications in the respiratory, cardiac, seizure and behavioral areas. Much of this is caused by the lack of neurological integrity of the severe and profound level of mental retardation. All of these factors make progress slow and call for patience, creativity, and flexibility.

To create home-like environments, to provide leisure time activities and six hours a day programming for this most complex and involved population has required a wide variety of creative and innovative approaches. Staff willing to work with this population had to be recruited and specially trained since most colleges and universities offer no program of study to prepare an individual to work with the severely and profoundly mentally retarded. Programs had to be designed, space had to be modified, equipment had to be adapted, and transportation developed. Even with all this it is important to understand that not all residents can tolerate six hours a day of programming, for some it is punitive and not medically sound. Even with all these circumstances, programming at Pineland is the most comprehensive available for the severely and profoundly retarded in Maine. At present, 246 residents receive over thirty hours of program per week; forty-six clients have been medically excused and/or recommended by the Interdisciplinary Team to have less than thirty hours of programming per week, however, twenty-nine of this group are receiving non-center based programming and seventeen attend a geriatric program.

During this period of change and development Pineland Center was required to work with other state and private agencies, the State legislature and a wide variety of public interest groups, all of whom had requirements and concerns.

## COMPLIANCE STATEMENT

I therefore submit to the Court that Pineland Center is in compliance with the standards of Appendix A.

However, I would like to inform the Court that Perry Hayden Hall, a resident building, has not been fully closed. Perry Hayden Hall at one time (1978) housed one hundred fifty-two residents. Today of the four residential units, two have been closed and the census has been reduced to thirty-six. The thirty-six residents residing in Perry Hayden Hall are profoundly multiply handicapped as well as retarded. The brain dysfunction, neurological problems and medical needs of the residents require complex management with the need for constant surveillance. Perry Hayden Hall I and II has been kept open as a residential unit because the physical plant is appropriate for the multiply handicapped persons living there. At the time the Consent Decree was entered into it was felt too costly to renovate Perry Hayden Hall. However since then the needs of the residents have determined the requirement to keep Perry Hayden Hall open. The environment has improved. Improvements for ventilation are being made and all windows in residential units will be replaced next year. The legislature has approved of this plan and money has been appropriated. In addition, the units have been painted, and the environment made more attractive and home-like. This is the least restrictive environment available. The open living room provides for interaction for the clients in wheelchairs or mobile carts, because of the complex adaptive equipment used in feeding, movement and treatment the open living room is needed. This open area allows for multi-purpose use. Outdoor living space is provided and most important day services are available in the building. Continuing evaluation and improvement will be made as client needs dictate.

One other area of noncompliance can be found in the section on medication, explaining in lay terms to the resident the effects of medication; where possible this is done.

I would also like the Court to know that because of the nature of the physical plant, the multiple handicaps and degree of retardation of the

clients, the complicated set of standards contained in Appendix A, and the various demands required and placed on Pineland Center that on a day-by-day basis if one were to apply a strict interpretation to the provisions of the Decree, all standards may not be in compliance. But, all the systems of compliance are in place.

## COMPLIANCE SYSTEMS

To monitor compliance with the standards of the Consent Decree, a number of systems to measure and evaluate have been developed and are now in place or soon to be in place. The following list of systems of compliance are in place:

1) The Interdisciplinary Team - recommends programs and solves problems

2) Individual Prescriptive Plan - habilitation and treatment in least restrictive setting

3) Needs Assessment of residents - progress toward community placement

4) Certification as an Intermediate Care Facility for the Mentally Retarded

5) Monitoring Tool of individual standards

6) Full-time resident advocate

7) Human Rights and Assurances Committee

8) Consumer Advisory Board, as specified in Appendix A

In addition to the systems of compliance in place, it is important to note that an appropriate budget, staffing levels, equipment, supplies, vehicles, facilities, programs, and training for staff are all in place and adequate to meet the requirements of Appendix A.

Pineland Center has also complied with Plan of Correction (15) of the Stipulation Agreement. The planning committee was re-established and a tool was developed and implemented to ascertain the current needs of all residents for progress toward community placement. Responsibility for the implementation and design plan shall rest with the Bureau of Mental Retardation.

## SUPPORTING DATA

Reproduced on the following page is the Table of Contents of two large notebooks that contain backup material supporting this report which have been submitted to the Office of the Special Master.

## FUTURE DIRECTION of PINELAND CENTER

The future of Pineland Center points to a facility that will become more specialized, serving multiply handicapped individuals on a short-term or outpatient basis. Pineland Center with its highly trained staff and specialized

TABLE OF CONTENTS

Residents Rights . . . . . A
Environment . . . . . B
Staff Responsibilities, Staff Ratios . . . . . C
Programming . . . . . D
Personnel - Recruitment, Screening, Training, Qualifications, Termination. . E
Food, Clothing, Hygiene . . . . . F
Education . . . . . G
Recreation . . . . . H
Dental Services . . . . . I
Psychological Services . . . . . J
Physical Therapy Services . . . . . K
Speech Pathology and Audiology Services . . . . . L
Medical and Nursing Services . . . . . M
Restraints and Abuse . . . . . N
Medication . . . . . O
Behavior Modification, Research, and Hazardous or Experimental Treatment . . P
Maintenance, Safety and Emergency Procedures . . . . . Q
Labor . . . . . R
Records . . . . . S
Consumer Advisory Board . . . . . T
Management . . . . . U
Integration with the Community . . . . . V
Miscellaneous . . . . . W
Index . . . . . X

resources will become a comprehensive research and training center, developing programs and tools for use with clients with special medical, behavioral, educational or vocational needs. These services will be available to clients residing in the community. Training programs for staff at Pineland Center, parents and providers in the community will be developed and available through outreach efforts just beginning. As the community programs continue to grow and develop, Pineland Center will become a backup and support center offering emergency and respite care for when such services are unavailable in the community.

New techniques and methods will be researched and implemented at Pineland Center and then made available to the community.

To provide college and university students and faculty with experience in working with severely and profoundly mentally retarded multiply handicapped individuals, affiliation and training programs will be expanded.

Staff training programs utilizing a competency based system will be developed in cooperation with the universities and colleges in the area.

Genetic counselling and research will be expanded and new medical innovations in the treatment of this multiply handicapped population will be available.

Many of these future directions have already begun.

## ACKNOWLEDGEMENTS

I would like to acknowledge the many individuals, groups and agencies that have made compliance possible.

First I would like to acknowledge the late Governor James B. Longley for his enthusiastic support of programs and services for the mentally retarded and for his concurrence and support of the Consent Decree;

The former Attorney General and now Governor Joseph E. Brennan for his willingness to consent and to support the ideals of individualization and personalization of services for the mentally retarded of Maine;

Kevin Concannon, Commissioner of the Department of Mental Health and Corrections for his hard work and personal support. Ronald Welch, Bureau of Mental Retardation Director and the Regional Administrators;

The most hard working, dedicated and enthusiastic staff a person could possibly have--all the Pineland Center Staff--without their creative ideas, patience, love, hard work and resolve, compliance would not have been possible;

The Pineland Parents and Friends Association, the Consumer Advisory Board, the Maine Committee on Problems of the Mentally Retarded, Evelyn Sienko and her staff in the Licensing and Certification Division of the Department of

Human Services, William Laubenstein in the Attorney General's Office, the former Court Master David Gregory for his convictions, and finally the present Special Master, Lincoln Clark for his vision and understanding of the nature of the issues.

Submitted by:

George A. Zitnay

George A. Zitnay
Superintendent
July 7, 1981

## 3. Auditor's Report

### PURPOSE

This audit was requested by Dr. Lincoln Clark, Special Master of the United States District Court in the case of Martti Wuori, et al v. Concannon et al. The purpose of this audit is to provide an independent review of the report of the Superintendent of Pineland Center relating to its compliance with the provisions in Appendix A of the Consent Decree. This audit was conducted on July 7, 8, and 9, 1981 by Robert H. Audette.

### QUALIFICATIONS of the AUDITOR

Education: B.S. in special education (emphasis in mental retardation)
Fitchburg State College, Fitchburg, Massachusetts

M.A. and Ph.D. in special education (emphasis in mental retardation and management issues)
Vanderbilt University, Nashville, Tennessee

### CURRENT EXPERIENCE

Parent of a son with mental retardation

Associate Professor of Education, Division of Special Education,Syracuse University

Director of Syracuse University Regional Resource Center serving New York, New Jersey, Puerto Rico, and the Virgin Islands

### PREVIOUS EXPERIENCE

Teacher and Director of Staff Development
Clover Bottom Hospital and School for the Mentally Retarded
Nashville, Tennessee

Assistant Superintendent
Walter Fernald State School
Waltham, Massachusetts

Associate Commissioner of Education Division of Special Education
Commonwealth of Massachusetts

Special Master to the Third Federal District Court
in the case of Haldeman v. Pennhurst

Court Appointed Expert in the Sixth Federal District Court in
the case of Mattie T v. Holloday

## PROCEDURE EMPLOYED in the AUDIT

Consultation with the Special Master.

Review of the provisions in Appendix A of the Consent Decree.

Review of the reports and supporting data provided to the Court by the Superintendent of Pineland Center.

On site inspection of Pineland Center including:

1) a review of the physical plant as well as programming and living environments;

2) interviews with residents, administrators and direct care staff, and superintendent;

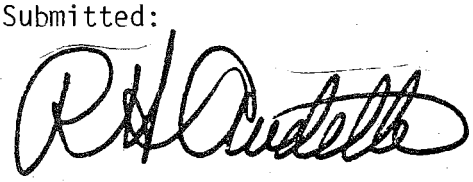
3) interview with the Advocate of Pineland Center;

4) interview with the plaintiffs' attorneys.

## FINDING

The reports and supporting data submitted to the Court by the Superintendent of Pineland Center accurately portray the conditions and programs at the Center. All of the systems referenced in Appendix A of the Consent Decree have been developed, staff have been trained in their implementation, and all of these systems are currently being carried out. Pineland Center is in compliance with the provisions in Appendix A of the Consent Decree.

Submitted:



Robert H. Audette
Auditor
July 9, 1981

## SECTION III PLANS OF CORRECTION

The parties signed a Stipulation Agreement on January 14, 1981 in which the defendants agreed to develop plans to correct the deficiencies perceived to exist in the community mental retardation system which are listed in the Stipulation Agreement. It was the intent of the parties that once developed and implemented, these Plans of Correction would be "systems of compliance" which would aid in achieving full compliance with the Consent Decree. A summary of the Plans of Correction and their status follows:

(1) All clients shall be removed from Seven Elms Boarding Home, Willowcrest Boarding Home, and Hilltop Boarding Home.

Status. One client remains at Seven Elms. She has had three preplacement visits and will be placed by July 15th. Three clients remain at Willowcrest. One client is on the waiting list for the Legace Home that will open in one month. One client had an Interdisciplinary Team meeting on June 19, 1981, for the purpose of recommending a residential placement. One client remains at Hilltop. Defendants are submitting further documentation on the needs of the clients who remain, and a discussion of further progress under this plan is scheduled for the August meeting with the parties.

(2) After an evaluation of the residential and program services provided at Ward's Home, Pinkham's Home, and Northland Manor, all clients shall either be removed or offered suitable programs.

Status. Three consultants were retained to evaluate the services in these homes. Their reports identified greatest needs in the area of staff training and community integration. Defendants thereafter submitted a plan for removal of all clients from Pinkham's Home by August 1, 1981, and for improving services at Ward's and Northland. Plaintiffs have submitted comments on the adequacy of the plans respecting Ward's and Northland, and the defendants are preparing responses to the comments.

(3) The population shall be reduced and/or the level of programming for clients shall be increased at the under-listed homes.

Status. Plans of correction and appropriate agreements have been made to increase the level of active programs at Tissue's Boarding Home, Hall Dale Manor, Noyes Boarding, Houlton Residential Center. Seven out of ten clients have been removed from Bruce Haven. The remainder will be placed by September.

These plans principally address the development of habilitation plans and staff training. On July 13, 1981, plaintiffs submitted comments on the need for development of habilitation plans for Activities for Daily Living and implementation of the Decree regarding procedures governing waivers of out-of-home programming.

The parties have discussed but have not yet reached final agreement on the timetable for full implementation of this plan and subsequent procedures for reviewing compliance.

(4) A case review will be conducted for all clients in nursing homes that serve predominantly non-mentally retarded individuals. Upon completion of the case review, clients recommended for replacement shall be moved. Clients not recommended for replacement shall be reviewed by an on-site professional team for purposes of recommendations to upgrade programming.

Status. Case record and on-site reviews have been concluded and defendants have prepared a plan for meeting the identified needs of clients. Plaintiffs are preparing comments on the plan.

(5) After a case record review, the Prescriptive Program Planning process shall be re-examined, and when necessary, restructured. A consultant has been employed to undertake the review and make recommendation.

Status. The re-examination by a professional consultant is underway.

The deadline for the final report was extended by mutual consent in order to accommodate the consultant.

(6) The impact of the revised Prescriptive Program Planning process shall be statistically evaluated and further revised in accordance with the evaluation.

Status. This task is scheduled to commence after completion of Plan (5).

(7) The Consumers Advisory Board shall be assisted in making trained Correspondents available to participate in the Interdisciplinary Team meetings of all clients who are not able to advocate on their own behalf.

Status. A plan by the Bureau of Mental Retardation has been approved by the parties and has been submitted to the Consumers Advisory Board to seek its agreement. The plan includes ongoing training. All contracts have been made; a brochure has been printed; a training workshop has been scheduled for some time in September at the Consumer Advisory Board's request.

The parties have discussed but have not yet reached final agreement on the timetable for full implementation of this plan and subsequent procedure for reviewing compliance.

(8) Plans shall be developed to bring into compliance with the Decree the programs serving clients in these agencies: Bangor Rehabilitation Center, Goodwill, Coastal Workshop, Pathways, Winthrop Work Activity Center, Green Valley.

Status. Three professional consultants have been engaged to review the programs of these agencies. Introductory and case record reviews have been concluded. The consultant who was retained for overall assessment of the programs is developing a measuring instrument. His report will be prepared in September and defendants' plan is due by November 15, 1981. The deadlines were extended by mutual consent in order to accommodate the consultants.

(9) An instrument shall be developed to identify unmet residential and programmatic client needs, by type and location. This instrument shall be utilized to determine and aggregate these needs, and to develop a plan for resource realignment or development where necessary.

Status. The instrument has been developed and the data have been collected and partially aggregated. The professional consultant has visited the State, and preliminarily reviewed the data. His draft report is due by August 1,

1981, and the defendants' plan by mid-September. These deadlines were extended to accommodate the needs of the consultant.

(10) A plan shall be formulated by designated representatives of the disciplines of psychology, occupational therapy, physical therapy, and speech therapy to recruit, develop and utilize the professional resources of their State and national organizations for the benefit of the Decree's class members.

Status. The professionals have been chosen and are in the process of surveying 700 professionals in Maine to ascertain their competence and interest in rendering services to the mentally retarded. Due to time constraints and the massiveness of the data to be printed, the final resource list will be out by the end of the summer.

(11) Quarterly reports shall be made on problems and progress toward the alleviation of deficiencies in the following areas: transportation, crisis intervention, family support, respite services, and community recreational opportunity.

Status. The first set of quarterly reports were submitted. After discussion at a meeting with the parties, the defendants agreed to include provisions for the development of Decree compliant crisis intervention services in the next set of quarterly reports. Second quarterly reports have been received for all regions.

(12) A plan shall be formulated to track clients' needs and for resource development.

Status. Defendants received an extension of the deadline to September 15, 1981, so that the plan may include provisions for monitoring systems developed pursuant to Plans (5), (9) and (14) and so that it might incorporate the recommendations of the consultant retained pursuant to Plan (13).

(13) A plan shall be developed to improve monitoring systems of services delivered to clients, to assure the quality of the services, and to provide for prompt identification and correction of deficiencies.

Status. A professional consultant has been retained to evaluate the systems and develop a plan. The work is in progress, and a report is due by August 15.

(14) A plan shall be developed for training all employees and service providers to meet Decree standards and the purposes of the several Plans of Correction.

Status. A plan has been submitted for the training of service providers. Units delivered and competencies achieved will be monitored on an ongoing basis through use of the systems developed pursuant to Plans (12) and (13).

The parties have discussed a timetable for full implementation of this plan and subsequent procedures for reviewing compliance. Final agreement has not yet been reached.

(15) Pineland Center shall re-establish its Planning Committee to ascertain the best suited community placement for each current resident and transmit its findings to the BMR for incorporation in a long-term community development plan.

Status. The Committee has been re-established, the data have been collected, and the data are currently being key-punched. The information from this is being correlated with the overall resource development plan under Plan (9) so that residents of Pineland will be included. This plan is due September 15, 1981.

## SECTION IV OBSERVATIONS

### 1. Two-Way Door Policy.

In years gone by, Pineland Center was an institution with a one-way door; the mentally retarded who entered through that door were committed to spend the rest of their dreary lives within. As Maine's total population grew, so did the number of retarded persons. Pineland became increasingly overcrowded, reaching a peak population of 1478 clients in 1955, and then declined to 431 in 1978. This rapid exodus happened, to put it crudely,by virtually dumping clients into the community. Because of the insufficiency of community day programs, one may wonder how beneficial the transfer was for the clients. In July, 1978, the Court held that still further progress was required both at Pineland and in the community. The Decree set a ceiling of 350 clients for Pineland; its population is now 344. A fine achievement! The old one-way door is a two-way door now, and the new policy is "Admit, train, and return them promptly to the community.

Now again, however, a long list of applicants await admittance to Pineland to receive the benefits of its specialized services. Some of these people have never been admitted to Pineland before, and others have been placed in the community but need to return to Pineland for short, or in a few cases, long-term stays.[1] Of the present residents, only a few, because of declining health, will probably have to remain indefinitely; some residents are ready to be discharged now, and others will be ready in the near future, but discharges are being delayed because of a lack of openings in community residential facilities and day programs.

The two-way door needs oiling. Too few residents are entering and leaving. In the past year the population at Pineland Center has been more stable than for many years. The number of class members transferred from Pineland Center to community residences in 1979 was 64; in 1980, 58;and through June, 1981, 25.

The following observations deal primarily with problems which, as they are resolved, will speed up the transfers.

### 2. Discrimination between classes of clients.

In making transfers and providing services, Pineland and all community agencies serving class members must conform to the requirements of the Decree. The Special Master's responsibility is limited to class members, yet he feels obligated to voice his concern that class members receive preferential treatment in community placements, habilitation programs, and transportation arrangements. Of a total of about 2600 clients served by the Bureau of Mental Retardation, class members number only about 1000; morally, if not legally, preferential treatment for them is wrong. Although every employee of the BMR with whom the issue has been discussed deplores this kind of discrimination, at times it has been condoned in order to achieve technical compliance with the Decree. The Bureau of Mental Retardation should issue a forceful policy

---

1. A poignant example is that of Martti Wuori, whose name heads the list of plaintiffs in this case. After he had been placed in a community residential facility, an Interdisciplinary Review Team concluded that his placement was not a success. A Maine District Judge concurred, and so Martti Wuori has been returned to Pineland Center.

statement emphasizing that all of its clients shall receive equal treatment, in conformance with Decree standards, without regard to their Decree class. Such a statement might forestall the possibility of a petition to the Court to bring about equal treatment for all clients.

3. Communitization Policy.

The Bureau of Mental Retardation has the responsibility for the communitization of Pineland clients. It is a hard task to do well. The following quotation is a good summary of the desirable policies.

> "In establishing community homes for retarded persons, planners should keep in mind that a home is a place to sleep, a place to eat, a place to find respite, a place to find acceptance and companionship, and a place to regenerate one's strength.
>
> The less emphasis placed on "program", and the more emphasis placed on "home," the more successful the residence seems to be.
>
> Too much reinforcement of day programs in the home, or emphasising the training aspects of a community residential program may result in depriving the residents of the basic needs the home is supposed to meet.
>
> Consequently, most formal training and education should take place outside the home. Whatever education, training and development that must take place at home should be done in a natural, informal fashion in an atmosphere of love, acceptance, and genuine human concern.
>
> Any services which are not normally provided in people's homes, such as social work counseling and psychological testing, should be performed away from homes for retarded people, too.
>
> Planning agencies should also be mindful of the number of people who will share the residence. Large community residential facilities, like the institutions they are intended to replace, have a tendency to become impersonal. When they are too big, a certain regimented, institutional routine can creep into the operation. Also, as staffs become larger, formal labor-management practices develop which take away from the home atmosphere.
>
> There is a need for a variety of community residences appropriate to the individual retarded person's requirements. And community services must be supportive of these homes. Well planned, interdisciplinary developmental programs appropriate to each retarded person's age and level of functioning are a necessary element in successful community living.
>
> Any plan for housing should take into consideration the fact that the mentally retarded person, whether an infant, a child, an adolescent or an adult, is first a human being and only incidentally retarded. Though he requires specialized services, his basic needs are remarkably similar to those in his age group.
>
> As an infant, the retarded child is best served in a family setting that offers stimulation, interpersonal relations, warmth and affection.

As a child and into adolescence, he deserves the same opportunities to grow, and learn as his peer group. As an adult, he should be afforded the same right to contribute, within his capabilities, to his own and to his community's development. And in old age, he deserves respect and the comfort and security that come from still being a part of a family or a small group, and of being a member of the community.

In short, he has a right to be a part of society -- not apart from society."[1]

4. Grants to Parents.

All parents want the best possible life for their children, but parents of a retarded child have much more difficulty deciding what is right. A frequent problem is whether it is better to keep the retarded child at home or to place him in another residential setting. Help in solving this problem is available from the regional offices of the Bureau of Mental Retardation. For parents who want to keep their retarded child at home, but feel forced for economic reasons to turn him over to a public agency, grants-in-aid can provide needed financial relief. Grants might also induce some parents to take back into their homes children who are presently in Pineland or in some community residential facility. Attached to all such grants should be a condition that the parents periodically attend training programs to learn the modern techniques of habilitating the retarded. This stipulation might also stimulate parents to increase their support of the day programs, which are typically understaffed and underfinanced.

A more liberal grant-in-aid policy to enable parents to keep their retarded child at home would often be not only in the best interest of the child, but is by far the least costly of the alternative ways to expand housing for the retarded in the community.

5. Encouragement of Independent Living.

Independent living is the ideal end of habilitation. Most persons at a certain stage in their lives leave the "nest" to live in a home or apartment of their own. This is feasible for many retarded persons. Not only is it better for the retarded, but it is also less costly than other types of community residential facilities. A more liberal policy of housing subsidies is needed to promote independent living for retarded persons.

6. Establishment of H.O.M.E.S.

No one type of community residential facility is, of course, most suitable for all retarded persons. The abilities, personalities, and desires of retarded people are as varied as those of the non-retarded.

Maine has about ninety foster homes for one, two or three retarded persons. Although foster homes have often suffered opprobrium in the press, many are providing affectionate care and are offering new horizons in a minimally restrictive environment.

---

1. President's Committee on Mental Retardation, 1975.
It may be noted that this quotation overlooks in-home programming--habilitation programs are required for client growth.

Successful foster home placement requires thoughtful matching of client and home. A promising experiment with foster homes -- Homes of Maine Encouraging Self-Sufficiency (H.O.M.E.S.)-- is scheduled for ten mentally retarded persons, to be chosen from sixty candidates now at Pineland.

A H.O.M.E.S. developer in the Augusta regional office of the Bureau of Mental Retardation is to recruit candidate homes in places where transportation arrangements can be made for clients to participate in day programs. Many Maine families, beset by inflation, would welcome opportunities to earn additional income; a number of these families have the necessary interest and the space to take a retarded person into their home. The H.O.M.E.S. developer will train each chosen host family in its responsibilities, and will ensure that placement is consistent with the desires of the client or the client's guardian.

In addition to identifying and preparing clients for placement in H.O.M.E.S Pineland Center is to develop Individual Program Plans for each client. These plans set forth what should be done to habilitate or rehabilitate the client, including procedures for respite,[1] readmission, and other specialized back-up services by Pineland. To measure the effectiveness of the H.O.M.E.S. experiment, each client will be scored on an "Adaptive Behavior Scale prior to placement, and periodically thereafter.

The cost for H.O.M.E.S. would be considerably less than the cost of keeping a client in Pineland or in other residential alternatives. It is hoped that the bureaucratic delays that inevitably precede the launching of any new program will soon end, so that the H.O.M.E.S. program can soon start. Once cleared, the program can be implemented in ninety days.

7. Support for Group and Boarding Homes.

In Maine, there are 3,478 licensed boarding home beds serving all population groups. Of these, about 600 beds are in sixty-eight group and boarding homes serving primarily the mentally retarded. They comprise the largest sector in Maine's network of facilities for the retarded, yet they have been the orphans of the network. Some existing group and boarding homes, including excellent ones, are on the verge of closing down because the State's reimbursement of their costs has not kept up with inflation.

The Office of the Special Master has received more grievances from group home providers than from any other category of residential providers.

The moratorium on the construction and expansion of group and boarding homes recently promulgated by the Maine Department of Human Services is a severe inhibiting factor for appropriate community placement of the mentally retarded.

---

1. Respite is the short-term alternative placement of a client in another residential facility. Respite is needed periodically for the sake of the client and for the residential providers. As a grim example, there is a case of parents who have never left their home together since their child was born. One of the parents has been with the child, now an adult every night for over twenty-five years. They deserve and need a vacation together!

Group homes are a necessary part of Maine's system for the retarded. They warrant support because: (1) some Pineland clients are better qualified for admittance to group homes than to other types of community facilities; (2) Pineland has a waiting list of retarded who cannot be admitted until existing clients are discharged; and (3) group homes are desirable from a "cost-benefit" point of view.

The physical conditions of a group home are of less importance where a suitable day program is available and the residents are healthfully fed and clothed. Placement in a group home is generally preferable to institutionalization.

To assure the continued operation of existing group homes and to encourage the establishment of new ones to care for the mentally retarded, the State should revise its cost reimbursement schedule so that it relates to the quality and quantity of services provided. Reimbursement is now based essentially on just the number or residents in a home. There should be supplemental compensation to cover the cost of fulfilling the terms of service agreements between the State and the home. Many homes currently do provide habilitation services for their residents -- it would be advantageous to give them an incentive to do more. The service agreements would be monitored by case workers of the Bureau of Mental Retardation.

The Special Master feels he should express his opinion that there is a strong need for stepped up action on the part of all decision makers to examine and implement further resource development for group and boarding homes. A promising sign on the horizon is the recent legislative decision to form a special study group composed of members of the Joint Standing Committee on Health and Institutional Services and the Joint Standing Committee on Appropriations, Departmental and agency representatives, and consumers, to examine all aspects of group and boarding homes. The Bureau of Mental Retardation, Department of Mental Health and Corrections has, and will continue to vigorously support this action.

There is reason to hope that this action will further the development and the fiscal stability of group and boarding homes in Maine. They are in sore need!

8. Revision of ICF/MR Regulations.

"De-institutionalization" is generally acknowledged as desirable for the maximum development of retarded persons. Community residential facilities for the severely retarded, however, require more staff and services than other types of community residential arrangements. Major credit to provide such care goes to the previous Special Master for the initiation of the system of "Intermediate Care Facilities for the Mentally Retarded (ICF/MRs)" in Maine. Since 1979, twenty-two ICF/MRs have been organized. They are governed by regulations of the Maine Department of Human Services, with 70 per cent financing by the Federal government and 30 per cent by the State.

Despite the need for more ICF/MRs, several potential providers have not applied for a license because they have heard about the pains of the present ICF/MRs. Their root problem is both the perceived and actual regulations and principles that govern their operations. The ICF/MR regulations and principles of reimbursement, in part adopted from a nursing home model, are not entirely suitable to cover the needs of the mentally retarded. As one small example,

ICF/MRs, which often care for young, hyperactive retarded, could not adequately feed their clients for the $2.23 per day that had been determined as sufficient for geriatric ICFs. When this was called to the attention of DHS executives, the situation was corrected, with the significant and proper policy statement that, if costs for caring for the retarded are higher than those for geriatric clients, the difference in costs will be met.

The Department of Human Services has expressed its willingness to respond immediately to articulated concerns of clients and providers; and to undertake, in the fall, a review of the entire ICF/MR Program. This review should result in the removal of inconsistencies with the provisions of the Consent Decree. (See Appendix A-30).

9. Incentive Policy for Day Programs.

The mentally retarded who live in the community may attend a variety of day programs designed for their different needs and abilities. These programs include: (1) Fundamental Life Activities; (2) Practical Life Activities; (3) Personal/Social?Independent Living Skills; (4) Work Activities; (5) Work Adjustment Training; (6) Sheltered Employment; and (7) Vocational Evaluation. The programs are operated by State or non-profit agencies, and financed by fees, private contributions, and grants from public agencies.

Day program providers face mounting problems as clients are released from Pineland to community residential facilities. Of real concern are the grant-in-aid policies of the Bureau of Mental Retardation, the Bureau of Rehabilitation, and Title XX. Providers feel that grants are based primarily on the projected deficit of the providers' budgets. Since the budgets are required to include all projected income and expenses, the income projection must show private contributions as well as receipts from public agencies. The effect is to inhibit community fund-raising: "The more we raise, the smaller the grant." This is a "disincentive policy."

The first requirement to change from a disincentive policy to an incentive policy would be to allow providers to exclude private contributions from their budgets of projected income. Then the State grants would be awarded in the minimum amounts needed to meet the Generic and Specific Standards for Adult Community Programs that are required to meet the provisions of the Consent Decree. Since there is considerable variation in the level of services provided, such a policy might result in smaller grants to some day programs and larger grants to others. Then it would be up to the day program providers to persuade their communities to finance services over and above the minimum standards. This policy would reward those communities that recognize and accept responsibility for their disabled citizens.

Understandably, local communities try to shift as much as possible of the financial burden to the State, and the State to the Federal government. The appropriate counter-strategy is an incentive policy that maximizes local support.

10. Opportunities of Pineland Center.

Coming into compliance with the Consent Decree is the result of monumental effort by the staff of Pineland. Now that the systems of compliance are in place, there are exciting challenges to expand existing services and develop new ones. In accepting new challenges, increased regard should be given to Pineland as an integral part of the statewide system.

(a) Training and Research. The continual movement of clients from Pineland will require an ever-increasing number of workers in community facilities. The work is hard, the pay is low, the turnover is high. More and more training will be required. There is also a large need for training of "correspondents," who, under the aegis of the Consumers Advisory Board, have the responsibility for surveillance of the rights of clients.

Pineland staff have conducted some training sessions at Pineland and in communities. They have also prepared manuals for training personnel and for habilitating clients. Seminars, workshops, and self-teaching programs can be developed at Pineland. It is now time to develop at Pineland a more systematic and complete program for training and for research on the effectiveness of training methods.

Progressively, additional training programs will also be developed in the community.

(b) Genetic Research and Counseling. A relatively new approach to the problem of mental retardation lies in genetic research and counseling of prospective parents. As one example, some parents need warning of the dangers to the fetus caused by alcoholism. Expansion of Pineland's genetic research and counseling services should be encouraged as a promising means of prevention and treatment of mental retardation.

(c) Cooperation with Colleges and Universities. Pineland Center has arranged many cooperative projects with colleges and universities in the area (Bowdoin College, Westbrook College, University of Southern Maine, University of New England, Bangor Community College, Tufts University, University of Vermont). These projects are mutually worthwhile, not only for their short-term benefits, but also as a means for increasing the public's understanding of the problems of the developmentally disabled, and for encouraging students to enter the field to help solve them.

(d) Certification Procedure. Admission into Pineland Center is governed by the certification procedure specified in M.R.S.A. Para. 2659-A et seq. The purpose of this Statute is to protect the rights of an individual who is being considered for commitment to a State institution. The Statute does not govern admittance to community residential facilities not operated by the State.

The present certification procedure is cumbersome, expensive, and time-consuming. A typical certification hearing required hours of preparation and involves eight to a dozen or more persons: a judge, lawyers, psychologists, social workers, advocates, correspondents, parents, guardians, and the prospective client. Lawyers sometimes do not even know whether their duty is to seek or to prevent certification of their client. Many people have complained about the procedure, but nobody has done anything about it. Pineland Center is the most appropriate agency to take the initiative for the development of a simplified certification procedure that will protect the rights of institutionalized persons. The research has already begun. Since a decision to "certify" an incompetent person is, in reality, an involuntary commitment, the State court will continue to be involved. A new, simplified certification procedure would require legislative action.

(e) "Maine Developmental Center". The name of an institution is important. When founded in 1908, Maine's institution for the mentally retarded was "Maine School for the Feeble Minded". In 1925 it was changed to "Pownal State School". In 1962 it became the "Pownal Hospital and Training Center and in 1973, "Pineland Center".

When an institution has gone through a substantial reorganization, it is good practice to signify the change by giving it a new name, in order to alter its public image. The scope of activities at Pineland Center has broadened and deepened to focus on the development of its residents' abilities and through its outreach and community training programs. It is strongly urged that it is timely to consider another name change, for example, the "Maine Developmental Center".

# APPENDICES

Memoranda on some of the problems addressed in the last six months are reproduced in the Appendices. It will be apparent that several of these problems are still unresolved.

To: Ronald Welch
From: Lincoln Clark
Subject: Personnel Requirements

From reading the "Quarterly Revision of Compliance Plans" this question came to mind: are there sufficient personnel to carry out the decree requirements?

Would it be too much to fill out a table like this in whole or in part?

Personnel Requirements and Vacancies

| Job Classification | No. MBR Employees | | | ICF/MR | | | Other Homes | | |
|---|---|---|---|---|---|---|---|---|---|
| | Need | Empl. | Vacan. | Need | Empl. | Vacan. | Need | Empl. | Vacan. |
| _____ | | | | | | | | | |
| _____ | | | | | | | | | |
| _____ | | | | | | | | | |
| _____ | | | | | | | | | |

Not only would this focus on vacancies to be filled but another use would be to have data to show to institutions like Westbrook College to train people for certain job classification.

# STATE OF MAINE

## Inter-Departmental Memorandum

Date 2/27/81

To Lincoln Clark, Special Master Dept.

From Betsy Davenport, FOM Dept. Bur. of Mental Retardation

Subject "Systemic Change" and personnel requirements

Ron has asked me to respond to your memo on systemic changes and personnel requirements. First, my apologies for the acronyms, I have tried to keep these to a minimum in writing this most recent round of compliance plan revisions. I have also changed the format in an effort to more clearly illustrate the flow of activity. You will note that the services enumerated in #11 of the Stipulation Agreement are addressed in the plan. I would appreciate feedback from you as to whether this information is sufficient.

Are these reports resulting in systemic changes?

Thus far, I have left it to the regions to determine the need for central office support or intervention. In most cases the regions prefer to work out problems at the local level. Each region receives a copy of all the regional plans. This has resulted in identifying some areas that require attention on our part.

The four of us at central office, following the completion of each round of quarterly revisions, develop an internal plan to address areas identified as needing our attention. It has generally been our experience that changes that are initiated at the regional level are more expeditious, and have greater long range effectiveness than those initiated at the central office level. This is particularly true of situations involving the central and regional office of other state agencies.

Attached is the information you requested on BMR personnel requirements along with the most recent revisions of the Region I Compliance Plan. I will be sending along the quarterly revisions from other regions as they are completed.

BD:cc

# BUREAU OF MENTAL RETARDATION EMPLOYEES

| Region | Position | Needed | Employed | Vacancies |
|---|---|---|---|---|
| | Bureau Director | 1 | 1 | 0 |
| | Resource Development Manager | 1 | 1 | 0 |
| | Guardianship Program Manager | 1 | 1 | 0 |
| | Field Operations Manager | 1 | 1 | 0 |
| | Regional Administrators | 6 | 6 | 0 |
| | Regional Supervisors | 6 | 6 | 0 |
| | Children's Services Supv. | 1 | 0 | 0 |
| Direct Service by Region | | | | |
| I | IPPC | 1 | 1 | 0 |
| | Caseworkers | 5 | 4 | 0 |
| | Child Development workers | 4 | 3 | 1 |
| II | IPPC | 2 | 1 | 1 |
| | Caseworkers | 8 | 7 | 1 |
| | Child Deve. workers | 4 | 3 | 1 |
| | Resource Developer | 1 | 1 | 0 |
| III | IPPC | 2 | 2 | 0 |
| | Caseworkers | 11 | 9 | 0 |
| | Child Deve. Workers (sub-contracted) | | | |
| | Resource Developer | 1 | 1 | 0 |
| IV | IPPC | 2 | 1 | 0 |
| | Caseworkers | 7 | 6 | 0 |
| | Child Deve. Workers | 3 | 3 | 0 |
| | Resource Developer | 1 | 1 | 0 |
| V | IPPC | 2 | 2 | 0 |
| | Caseworkers | 8 | 6 | 0 |
| | Child Deve. Workers | through Infant Development Program | | |
| | Resource Developer | 1 | 1 | 0 |
| VI | IPPC | 1 | 1 | 0 |
| | Caseworkers | 6 | 6 | 0 |
| | Child Deve. Workers | 4 | 3 | 1 |
| | Resource Developer | 1 | 1 | 0 |

# STATE OF MAINE

## Inter-Departmental Memorandum Date 4/30/81

To Lincoln Clark, Court Master Dept.

From Ronald S. Welch, Director Dept. Bur. of Mental Retardation

Subject Memo "Personnel Requirements"

In reviewing this memo, and our response to it, no indication was given as to whether or not on-going status reports on the filling of vacancies were requested.

Nonetheless, I would like to point out that I do keep abreast of vacancies in the system. This allows me to identify critical areas and to develop subsequent plans of attack. There are two basic dilemmas which tend to arise more often than others and which demand attention above and beyond the attention paid by management staff in the normal process of filling routine vacancies.

The first problem is one in which, for a number of unrelated instances, a particular program in the Bureau finds itself with an inordinate number of vacancies. Region II (Bangor) is currently working through such a situation. Arrangements have been made in that instance to provide (1) central office supervisory support, (2) a contingency plan to "borrow" staff from other offices should the need arise, and, (3) an understanding that should I or Commissioner Martel need to intervene with the Department of Personnel that that would be arranged.

The second type of problem relates to filling vacancies of "hard to fill" positions such as physical therapists and occupational therapists. We have continued to use an extensive (and expensive) advertising campaign, including personal recruitment, "free" visits to Maine, etc. In addition, Stipulation Agreement #10 will be addressing this issue in the form of concrete strategies and plans.

RSW:cc

cc: Karen Kingsley
Commissioner Concannon

United States District Court
Portland, Maine 04112



LINCOLN CLARK
SPECIAL MASTER

March 19, 1981

To: Ron Welch

From: L.C.

Subject: Habilitation after Communitization

So that I won't be pestering you too much I'd better get off to California soonest.

The essence of the consent decree is communitization and habilitation. The fountainhead whence all flows is the IDT -- it determines when and where and how the client should be "communitized" and "habilitated".

All the plans we are working on are attempts to provide input and to measure the input, but I do not see any measures of output, i.e. what has been produced, meaning, how much better off is the client than he was before the process was initiated?

There is provision for habilitation plans to be developed by ICF/MR's and day programs but if I am properly informed there is no standard form on which the habilitation plan is recorded, habilitation plans are not prepared for all clients and there does not seem to be any provision for analysis of the habilitation plans to determine to what extent the recommendations of the IDT have been accomplished. Without such analysis how will we ever know if our energy and money has done any good and how can we really justify the large cost to the taxpayers? I can conceive of a kind of efficiency ratio being developed: output/input, which would be the accomplishments of the habilitation plan divided by the specifications of the IDT.

The first requirement is a standard form. Enclosed is one which I picked up. (I understand that each home has to prepare its own form and some have spent hours arguing what it should be.)

The second requirement is instructions on how many habilitation plans should a client be subjected to at one time? In two homes that I visited they had decided on three.

The third requirement is who should establish the steps in the habilitation plan? The answer probably is the staff of the home or day program. The resource for such plans might be Pineland. For example they might recommend the steps to teach a client how to brush his teeth. The staff, however, would adjust this to fit the particular client.

The fourth requirement is the toughest -- to relate the information reported on the habilitation plan to the original IDT specifications. Couldn't a smart girl like Betsey solve this one?

United States District Court
Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER

Am I being too theoretical in my inexperience or am I on the right track that we've got to develop a scheme to measure results and results are not input.

It would be nice to find your answer in my mail when I get back April 16.

Enc.

# STATE OF MAINE

## Inter-Departmental Memorandum Date 3/25/81

To Lincoln Clark, Court Master Dept.

From Betsy Davenport, FOM Dept. Bur. of Mental Retardation

Subject Habilitation after communitization

I am responding to the memo you sent to Ron regarding habilitation planning. You are right on in saying we need to develop a scheme to measure results. This will be a major area of emphasis for our consultants under Stipulation Agreement #5. I have discussed what I perceive as our problems with our consultants. They have had experience in other states in dealing with creating a habilitation planning system that lends itself to monitoring (measuring) results.

We do have the necessary elements of a good system in place. The IDTs are consistently addressing and identifying areas of need. Participants in the IDT process are consistently willing to assume responsibility for identified needs. The system begins to break down in the level of specificity of the service objectives. This critical missing link causes a chain reaction of further breakdowns in the system. The lack of specificity in the service objective generally causes the habilitation plan to be deficient in specificity. It is then impossible to measure the results of those vaguely stated goals and objectives. Because the goals are generally not monitorable, staff usually find this task less than desirable.

I believe the consultants' work on the IPP process will accomplish what needs to be done. We need to:

1. teach IPP coordinators to write specific service objectives,
2. teach IDT participants to write habilitation plans with enough specificity to enable results to be measured,
3. teach the monitors how to measure results.

In that the accomplishments of the consultants' final product and training package is several months down the road, I will continue my work with IPP coordinators in improving the quality of the IPP. At their request, I am putting together a "model" IPP packet for them to use as a guide in improving their own work.

With regard to the requirements you listed in your memo, I have the following thoughts:

1. standard form - I am somewhat reluctant to require a standard. I have seen and have used a variety of hab plan forms. They all generally contain the same general elemen but are laid out differently. The layout is generally what makes one form more attractive to an individual than others. The critical element is the skills of the person writing the hab plan. We have a BMR hab plan form that is made available to providers. They have the option of using ours or developing their own. I would prefer to allow agencies the flexibility of altering the layout, so as to assure that it meets their clients' needs. Forms tend to become needs unto themselves. Perhaps we could simply require standard elements.

2. How many hab plans? This should be part of what is determined at the IDT. So much depends on the intensity of the program and the needs of the client. The decision should be based on the individual client's needs and the ability of the provider to address those needs. Realism is critical in making this decision.

3. The steps in hab plan process. Thrre are several pre-packaged task analysis of specific skills available. Pineland Center and the regions have copies of Program Guide Vol. II which contains step-by-step methods for teaching a wide range of skills. Many staff, both from agencies and BMR, have participated in Marc Gold training. This training teaches the skill of task analysis. We need to work on making sure providers (1) have access to pre-packaged materials, (2) have skills to tailor these materials to the individual client, and, (3) have training in doing actual task analysis.

I should point out that this treatment approach is not philosophically embraced by all providers.

We have provided training in hab planning to large numbers of providers, however, the turnover rate tends to dilute its overall effectiveness. We need to provide training in this area on an ongoing basis.

4. Relationship between hab plan and original IDT specification - you're right, this is the toughest one. As I mentioned earlier, the level of specificity is the key to making the total system successful. There is a fine line between "too specific" and "not specific enough". The IDT recommendations need to be specific enough to establish clear expectations for the habilitation plan, yet general enough to allow the provider some latitude in fulfilling the obligation. I have already mentioned the ramifications of vague recommendations. When recommendations are too specific, the provider responsible for the hab plan loses the flexibility to make minor changes without convening another IDT for approval. I am optimistic that with the skills we have within our system and the experience of our consultants, we can overcome these problems.

I hope I have responded to the points you have raised. Please keep the questions coming, as it is helpful to have someone keep <u>us</u> on the right track.

BD:cc

cc: Karen Kingsley
BLF consultants
Tim Wilson, Assoc. Comm.
Ron Welch, BMR Director

To: Ron Welch

From: Lincoln Clark

Subject: Distinction between types of DHS Regulations

I know that you are very conscious of ICF/MF complaints about ICF/MR regulations and would welcome amendments or interpretations that would facilitate their operations.

I also suspect that you are more aware than I that the complaints of the ICF/MRs fall into two basic categories: first are those that are equally applicable to nursing homes, second, are those that may be applicable to nursing homes but are not appropriate for ICF/MRs.

There was a good example at the meeting we both attended where Jim Lewis was the guest. You will recall the complaint about the $2.23/day allowance for food and the reluctance of dieticians to certify that the meals are adequate. Several arguments were made that the retarded need more food than elderly non-retarded. Lewis said he would investigate how the allowance of $2.23 had been determined. He implied that if he found the allowance was based on the cost of feeding elderly non-retarded and that the retarded require more food, the DHS should recognize the need and make the proper allowance.

Not only does this state a sound principle for the food allowance issue, but it might be a precedent for changing or interpreting other regulations where the needs of the retarded are significantly different from those of nursing home residents.

Doesn't this lead to three conclusions: (1) There should be a prompt follow-up on what is done about the food allowance as an issue for its own sake, (2) How the food allowance issue is settled may be an important precedent for other issues, and (3) We should give priority to those complaints about regulations that may be appripriate for nursing homes but are not right for ICF/MRs. (We can make the assumption that the nursing homes will carry the ball regarding regulations that they do not regard as appropriate. The ICF/MRs would get a free ride on anything they accomplish.

I would like to know what happens on the food allowance issue.

# STATE OF MAINE

A-11.

## Inter-Departmental Memorandum

Date 4/30/81

To Lincoln Clark, Court Master — Dept.

From Ronald S. Welch, Director — Dept. Bur. of Mental Retardation

Subject Memo "Distinction Between types of DHS Regulations"

---

In regard to the food allowance in the ICFs/MR, I have been informed by Jim Lewis that the average allowance used for geriatric ICFs will not be used for ICFs/MR. Payment will be based on actual cost, as determined at audit time, provided, of course, that all of the grocery receipts are not from the local imported gourmet store.

RSW:cc

cc: Commissioner Concannon
Karen Kingsley
Jim Lewis

# United States District Court
## Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER

April 23, 1981

TO: Ron Welch

FROM: Lincoln Clark LC

SUBJECT: Incentive Policy for Day Programs

I have drafted the attached statement mostly on the basis of what I learned in California.

While I anticipate that the Bureau would not adopt all of this plan because of the additional cost, would it not be feasible to make a beginning toward the adoption of an "incentive policy" as described in the statement? It should be recognized that Maine's present "disincentive policy" in some cases probably causes the Bureau to make grants that cover more than the minimum quality standards that would be specified by the Bureau.

cc: William Laubenstein

# United States District Court
## Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER

April 23, 1981

Minimum Quality Standards for Day Programs

A major obstacle delaying the transfer of long-term clients from Pineland into communities is the shortage of suitable programs in the communities to meet their needs. The shortage is basically a money problem.

A day program provider is a non-profit organization that renders one or more of the following six types of programs:

(1) Fundamental Life Activities - Training and services which are basic to self maintenance, self awareness and self motivation and which addresses psycho-social, sensory motor and physiological needs of individuals within a developmental range of 0 - 3 years.

(2) Practical Life Activities - To promote the application, adaptation and integration of developmental skills necessary for semi or independent daily living.

(3) Personal/Social/Independent Living Skills - To develop or modify a wide range of individual skills and behaviors in personal and social adjustment and community living skills, based on socially appropriate individual or group behaviors.

(4) Work Activities - To maximize individual functioning in personal development and community living, and to provide a regular program of work experience at an introductory level.

(5) Work Adjustment Training - To provide a substantial and remunerative work experience, to acquire good work habits and skills, to increase physical and emotional tolerance to work, to improve work related skills and to modify attitudes and behaviors which inhibit satisfactory work performance.

(6) Sheltered Employment - To provide employment of a continuous nature for individuals who are not capable of functioning in a competitive work force, within an environment which reduces the pressures of competitive employment.

United States District Court
Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER



There are 66 day programs with a capacity of 1577 clients in homes distributed as shown below:

| Counties | No. Programs | Capacity |
|---|---|---|
| Region I - Aroostook County | 5 | 116 |
| Region II - Hancock, Penobscot, Piscataquis, Washington | 15 | 286 |
| Region III- Kennebec, Somerset | 11 | 402 |
| Region IV - Androscoggin, Franklin, Oxford | 11 | 210 |
| Region V - Cumberland, York | 17 | 366 |
| Region VI - Waldo, Knox, Lincoln, Sagadahoc | 7 | 197 |
| Total | 66 | 1577 |

Funding of the day programs is from four sources: private contributions, local government, State and Federal grants. The typical financial procedure is that the provider submits a budget to the Bureau of Mental Retardation showing projected income and expenses, and almost invariably a deficit. The income lists what the provider expects to receive from private contributions, local government grants and what the State transmits from the Federal government. Then the Bureau and the provider negotiate an amount for the State grant. As this is usually less than the deficit projected, expenses are then cut back to balance the budget.

While it is sound policy for the community and State to share the financial responsibility for the day programs, the present procedure is "disincentive". The more the provider raises locally, the less the Bureau grants. An "incentive policy" should be adopted. This could be done if the State would assume the responsibility for the cost of minimally acceptable quality programs and the community's contribution would be to provide programs above "minimum quality". The incentive policy implies that the State should not dictate total program standards but a "floor of expectation", below which programming would not be permitted and above which the communities should be encouraged to aspire. This policy also implies that all funds raised locally should be excluded in arriving at the amount the State gives to the provider. The effect of the incentive policy is to provide program autonomy when the minimum program quality standards are met.

It is beyond the scope of the office of the Special Master to propose specific minimum standards for day programs. A model which the Bureau might consider has been developed by Ogle and Newman.[1]/

[1]/ Ogle, Michael E. and Newman, N., Minimum Program Quality Standards for Day Programs for Developmentally Disabled Adults, Santa Barbara: Tri-Counties Regional Center, February 20, 1980.

United States District Court
Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER



It covers:

1.0 Program Operations Standards
- 1.1 Number of Hours/Day Clients Receive Training
- 1.2 Number of Hours/Day for Staff Planning
- 1.3 Number of Hours/Day of Program Operation Time
- 1.4 Number of Days/Week the Program Operates and Clients Attend
- 1.5 Total Number of Days of Program Operation/Year

2.0 Program Staffing Standards
- 2.1 Number of Full-time Direct Service Staff Positions
- 2.2 Number of Full-time Supervisory Staff Positions
- 2.3 Number of Full-time Clerical/Secretarial/ Receptionist Staff Positions
- 2.4 Number of Full-time Bookkeeping/Accounting Staff Positions
- 2.5 Number of Full-time Program Managers
- 2.6 Number of Full-time Maintenance/Janitorial Services Staff
- 2.7 Number of Full-time Substitute Staff Positions
- 2.8 Minimum Education and Experience Requirement for Program Staff

3.0 Program Cost Characteristics
- 3.1 Staff Salary Schedule
- 3.2 Fringe Benefits
- 3.3 Holidays
- 3.4 Vacations
- 3.5 Rent/Lease Costs for Program Facility
- 3.6 Program Utilities
- 3.7 Building Maintenance Costs
- 3.8 Program Equipment
- 3.9 Program Equipment Repair/Maintenance Cost
- 3.10 Office Equipment
- 3.11 Office Equipment Repair/Maintenance Cost
- 3.12 Program Supplies
- 3.13 Office Supplies
- 3.14 Communication Costs
- 3.15 General Insurance Cost
- 3.16 Vehicle Costs
- 3.17 Staff Travel Costs
- 3.18 Depreciation
- 3.19 Conference and Inservice Training Costs

The illustrative form for recording the costs associated with meeting the quality standards developed by Ogle and Newman is:

Program Name: _____

Program Type: _____ Date Completed: ___/___/___

A. Staff Costs

## TUITION RATE DETERMINATION FORM

1. A.D.A.[1] = Average # Clients from 1/1/79 to 12/31/79 = _____

2. Direct Service Staff
   A.D.A. (from 1) _____ ÷ 6.5 (8)* x $1014.50= ..... $_____

3. Supervisory Staff
   A.D.A. (from 1) _____ ÷ 39 (48)* x $1359.5 =..... $_____

4. Clerical/Secretarial/Receptionist Staff
   A.D.A. (from 1) _____ ÷ 48 x $757.50..=..... $_____

5. Bookkeeping/Accounting Staff
   A.D.A. (from 1) _____ ÷ 80 (65)* x $918.50 =..... $_____

6. Program Managers
   A.D.A. (from 1) _____ ÷ 117 x $1771. . .=..... $_____

7. Sum of 2 through 6 = $_____

8. Maintenance/Janitorial Staff
   a) Square footage of program floor space =_____
   (a) _____ ÷ 2500 x 3.79 = ..... $_____

9. Substitute Staff (See forms)

10. Fringe Benefits
    20% x #7 (above) $_____..... $_____

B. Indirect Expenses

11. Monthly Rent/Lease Cost for Progarm Facility (attach copy of statement) $_____

12. Program Utilities (6 month average 7/1 through 12/31)

    Electricity..... $_____
    Gas..... $_____
    Water..... $_____
    Trash..... $_____

13. Building Maintenance Costs (attach itemized statement of materials & labor costs for 12 month period 1/1 through 12/31).

    12 month Building & Grounds Maintenance Cost $_____

    x .50

    $_____

    ÷ 12=..... $_____

14. Program Equipment

A.D.A. (from 1)_____ x $3.00 = $_____

15. Program Equipment Repair/Maintenance Cost (attach itemized statement of materials and labor costs for 12 month period 1/1 through 12/31)

12 month Program Equipment Repair & Maintenance Cost:

$_____

x .50

$_____

÷ 12=..... $_____

16. Office Equipment Repair/Maintenance Costs (attach itemized statement of materials and labor costs for 12 month period 1/1 through 12/31

12 month Office Equipment Repair and Maintenance Cost:

$_____

x .50

$_____

÷ 12 = ..... $_____

17. Office Supplies

A.D.A. (from 1)_____ x $2.00 = ..... $_____

18. Program Supplies

A.D.A. (from 1)_____ x $4.00= ..... $_____

19. Communication Costs

A.D.A. (from 1)_____ x$2.50=..... $_____

20. General Insurance Costs (attach copy of statements)

12 month insurance costs.....$_____

÷12= ..... $_____

21. Vehicle Costs

A.D.A. (from 1)_____ x $1.75=..... $_____

22. Staff Travel Costs

A.D.A. (from 1)_____ x $.75= ..... $_____

23. Depreciation (attach copy of depreciation schedule for the 12 month period 1/1 through 12/31).

12 Month Depreciation Total..... $_____

÷ 12..... $_____

24. Conferences and In-service Training Costs

A.D.A. (from 1)_____ x $5.00= ..... $_____

---

25. Sum of items 7 through 24=..... $_____

26. Monthly Tuition Rate Per Client = Item 25 ÷ A.D.A. =..... $_____

*Numbers in parentheses ( ) are to be used by WAC's and Workshops in calculating their monthly rate (e.g., in item #2 DTAC's and Other Vendors would use 6.5 but WAC's and Workshop would use 8.

[1]A.D.A. is calculated by averaging the number of clients in attendance to the program during a month (sum # clients in attendance for each day in the month and divide by the number of program days in that month) and calculating a monthly average by summarizing the monthly averages and dividing by 12.

United States District Court
Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER

It will be noted that Item #26 ends up with a monthly tuition rate per client. At the present time this rate varies from provider to provider but a move is underway to establish a standard uniform rate for all California providers. Variations from the standard rate would be made for differences in regional labor costs.

April 27, 1981

TO: Ronald Welch

FROM: Lincoln Clark

SUBJECT: DHS Disallowance of "Overtime" Labor Costs

Concerns have been repeatedly expressed by home providers regarding the DHS reimbursement disallowance of weekly compensation paid employees working an excess of forty hours. This policy was previously addressed in a memo to you regarding an appeal by Mrs. Kinnelly for reimbursement of "overtime" wages paid to an employee as required by the U.S. Department of Labor yet disallowed by DHS as "excessive and unreasonable".

Other homes are having the same problem. Labor Department officials conducting investigations of a home's payroll records have stated that compensation in the form of "time" in lieu of payment at a rate of "time and a half" as required by Federal law is illegal. Additionally, the home will remain liable for all back wages not paid in accordance with the "time and a half" requirement. The question is the propriety of DHS's policy of disallowing reimbursement of labor costs that are mandated by Federal law.

All employees working within the home are presumably covered by the Fair Labor Standards Act (Section 3(S)(5) Fair Labor Standards Act of 1938, as amended). Consequently, they are required by law to be compensated at a minimum rate of $3.35/hour (Section 6 (a), Fair Labor Stardards Act), and <u>may not</u> be employed in any work week longer than forty hours <u>unless</u> compensated for the excess time at a rate not less than 150% of the regular payment rate. (Section 7 (a)(1), Fair Labor Standards Act).

The State of Maine DHS Principles of Reimbursement were written to comply with Section 249(a) of Federal Public Law 92-603 and the regulations promulgated thereunder as published in the Federal Register, (41 Fed. Reg., July 1, 1976.) Both Federal regulations and the State Principles provide for payment of services on a "reasonable cost-related basis" (Principle #1000), including all allowable necessary and proper costs incurred in rendering services (Principle #1014). Federal regulations further indicate that a state may not set the reimbursement rate so low that such reasonable costs are not reimbursed (41 Fed. Regs 27302).

An obvious conclusion is that DHS should be reimbursing over-time conpensation when related to necessary and proper rendition of services. This raises the question whether the State has an obligation to assist those homes found liable by the Department of Labor for failure to pay over-time wages as required by law.

In the past, DHS has referenced Principle #4200 which allows reimbursement for one additional person at minimum wage if necessary and reasonable. Providers have agreed, however, that circumstances requiring the presence of familiar and trained staff preclude the use of a temporary additional person. While a Relief Fund is provided, this is barely sufficient to cover vacation, sick days and holidays for the current staff and could not support the "time and a half" requirement of Federal law. Because of unexpected problems requiring overtime services of staff people, the various uncompensated staff training orientation and workshop requirements and the increased enforcement of the Minimum Wage and Overtime Law by the Department of Labor, reasonable and necessary overtime must be reimbursed. Home providers cannot continue to circumvent Federal laws because compliance would not be State reimbursed.

The Department of Labor has on occasion agreed to forego enforcement of an employer's back wage obligations in consideration of his/her consent to comply in the future, but even then an employer would remain liable for individual actions filed by the affected employee(s). While the Department of Labor may overlook past transgressions, the providers and the State must recognize their obligation in the future.

I trust that you will be able to obtain a proper resolution of the problem with the DHS and look forward to hearing the result.

# STATE OF MAINE



## Inter-Departmental Memorandum Date 4/30/81

To Lincoln Clark, Court Master Dept.

From Ronald S. Welch, Director Dept. Bur. of Mental Retardation

Subject Memo "DHS Reimbursement Principles vs U. S. Department of Labor"

Please be advised that I have forwarded the package of materials from KVCRC to Bob Foster. In reviewing the issues related to this problem, I have advised Bob to determine which other agencies face a comparable dilemma. I know, firsthand, for instance, of the situation Community Support Services is in relative to this issue and intend to be present at the Administrative Appeal hearing which they have requested.

The locus of the problem is in the Principles of Reimbursement for Boarding Care. There is no apparent conflict between DOL requirements and the Principles for ICF/MR.

Bob is heavily involved in a number of major efforts at this point, including implementation of certain items of the Stipulation Agreement. I would expect, nonetheless, that we will have a more detailed response to you by June 1, 1981.

RSW:cc

cc: Commissioner Concannon
Karen Kingsley
Bob Foster

April 16, 1981

TO: Ron Welch

FROM: Lincoln Clark

SUBJECT: M. R. Offenders

The attached is the latest communication from T___ D___ following several discussions regarding the transfer of M.R. offenders to Pineland.

The basic isea is that such tranfers would
(1) reduce the overpopulation in the correctional institutions,
(2) provide a new function for Pineland,
(3) offer better opportunity to habilitate retarded clients than the correctional institutions,
(4) save the taxpayers money,

I thought that a consensus had been reached that the way to implement the idea is to begin with a test case. It would involve going through these steps:
(1) the Regional Office would apply to Pineland for admittance,
(2) Pineland would review the application and make arrangements for receiving the client,
(3) the Commissioner would indicate his approval to transfer the client from the correctional institution to Pineland if the District Judge should commit the client to Pineland,
(4) the District Judge would "hear" the case in accordance with the certification procedure and make the commitment,
(5) the transfer of the client would be effected by arrangement between Pineland and the correctional institution.

George Zitnay has indicated willingness to cooperate. Kevin Concannon has the authority to transfer clients. Judge Donovan has voiced support for trying it out.

R___ G___ may be an especially tough case, but if it could be handled, others should be relatively easy.

How is the discussion referred to in D's letter progressing?

cc: K. Kingsley

# STATE OF MAINE



## Inter-Departmental Memorandum Date 4/30/81

To Lincoln Clark, Court Master Dept.

From Ronald Welch, Director Dept. Bur. of Mental Retardation

Subject Memo "M.R. Offender"

As you know, there has been considerable attention paid to the development of an MR Offender program. While our attempts to develop a resource for these people have not met with manifest success, nor has there been any substantive success elsewhere in the country. We have, however, contacted several "experts" in this area.

One such person, Miles Santamour of the President's Committee on Mental Retardation, and a "national expert" on the subject, recommends that the M.R. offender can best be served in a rehabilitation program designed with input from M.R. professionals, but administered as part of a correctional program.

He does not include the "naive offender" in this group, but recognizes the need for alternate services for those who get in trouble with the law, but not as part of a conscious or pre-meditated act nor knowledgeable about the consequences of such an act.

George, Kevin and I do, in fact, see a potential role for Pineland in developing a service for the latter category of clients. While the client specified as currently residing at the Maine State Prison does not fit the need, there are, in fact, mentally retarded people known to our staff for whom such a Pineland Center based service would be appropriate.

The timetable for development of this program, however, must be compatible with our ability to address the needs of those people currently being served by Pineland. We are, in fact, making several changes at Pineland now in order to accommodate a reduction of 37 staff, as well as to prepare for additional demands we expect will be made on Pineland when President Reagan's so-called Economic Recovery Program goes into effect later this year.

We will continue to explore alternative missions for Pineland, but, certainly, as a second priority to stablizing and maintaining those appropriate services which we now are able to provide to our clients. I am not concerned, at this point, that the resources at Pineland will dissolve away as a net reduction from our programs overall. For example, while we are losing 37 positions from Pineland in the new biennial budget (assuming the Legislature passes it), we are, on the other hand, increasing the community programs by sixteen (16) staff and a half million dollars ($500,000). There was, in fact, a net increase in the system as a whole, and that in a time when many programs are going down the tubes.

RSW:cc

cc: Karen Kingsley
Commissioner Concannon

To: Ronald Welch

From: Lincoln Clark

Subject: Financial Health of ICF/MRs

We all want to see more ICF/MRs established, and function successfully. This is necessary both to satisfy the consent decree and to provide the best quality care for the retarded. It is not happening as fast as it should due to inappropriate regulations and inadequate financial planning.

The basic financial problem of ICF/MRs is insufficient working capital. Three of the main causes are: (1) the principle of reimbursing interest costs, but not principal, (2) the principle of retroactive reimbursement, and (3) the delay in receiving reimbursement, which forces the ICF/MRs to go to bankers who are reluctant to loan to an operation about which there is little guiding experience.

The result is to discourage the launching of new homes and to jeopardize the operations of existing homes.

Tri-partite Agreement.

As a means to deal with the problem, the following tri-partite agreement is proposed:

"DHS to advance 85% of an ICF/MR's monthly budgeted costs on the first of each month. The balance, as adjusted in accordance with its reimbursement principles, would be due on the first of the following month. The initial reimbursement, however, would be due on the first of the second succeeding month.

In consideration of the above, the ICF/MR to:
authorize DHS to make all payments directly to the ICF/MR's bank account, (2) establish an escrowed fund from the depreciation portion of DHS reimbursement payments which, after withdrawals by the bank for the principal portion of its mortgage installments, would liquidate the principal on the maturity date of the mortgage, and (3) authorize the bank to pay its monthly mortgage installments and its other costs that are payable less frequently than monthly, e.g., F.I.C.A., taxes, insurance.

Whereupon, the bank to extend to the ICF/MR a line of credit of 15% of its monthly budgeted costs. Repayment to be due upon receipt of the next DHS reimbursement payment."

The principal implications of this proposed tri-partite agreement are:

For the DHS. The amount of embodied interest lost by making 85% advances would be more than compensated by smaller interest costs on ICF/MR bank loans. The risk of an ICF/MR absconding with the advance, or going bankrupt within one month, or submitting more than 15% of disallowable costs, is minimal and is minimized further by the ICF/MR's authorizations to its bank and by the bank's scrutiny and participation.

For the ICF/MR. The requirement of an escrowed depreciation fund prevents the ICF/MR from getting into a progressively worse case flow position as the principal component of the mortgage increases over time. The cost and burden of paperwork in paying its less frequent than monthly bills are shifted to the bank.

For the bank. The additional business would justify its slight additional cost for computer processing and office paperwork. Moreover, the depreciation reserve cuts its risk in a 15% budget loan.

The Model.

DHS advances and bank's line of credit would help an ICF/MR get underway, but a still more important problem is the treatment of depreciation. To illustrate the problem we have constructed a model with these assumptions: An ICF/MR buys a property for $125,000 of which the home is valued at $113, 333 and the land at $11,667.

The ICF/MR accepts the bank's offer of an $85,000 mortgage to be repaid over 20 years in monthly installments, with 15% interest on the unpaid balance.

Amortization Schedule.

The bank would set up an amortization schedule similar to the first four columns of the attached table. It requires the 240 monthly payments of $1119.27 in Column (1). This amount derived by a mathematical formula.

The amount required for interest is in Column (2).

The portion of the installment applied to principal is in Column (3). It is the remainder after the deduction of interest. Thus, in Month 1, the entry is the difference between $1119.27 and $1062.50, or $56.999.

The Total Principal in Column (4) is the cumulative amount of the principal that has been paid. Thus, for Month 2, it is $56.77 + $57.48 = $114.25.

Reimbursement Principles.

Understanding the amortization schedule is a necessary foundation to comprehend the depreciation problem. DHS does reimburse interest, but does not reimburse principal. Therefore, in order to meet the mortgage installments, the ICF/MR must also pay the principal portion of the installment.

In lieu of reimbursing principal, DHS reimburses for the depreciation of the home, but not land. It specifies the "straight-line method" of depreciation, which allows the same amount each month. The amount is obtained by dividing the net value of the home (the original value less its estimated salvage value) by the number of months of its useful life. Of course, it is impossible to make an accurate prediction of the salvage value of a home or of its "useful life", or how much must be spent during its useful life for necessary capital replacement, e.g., a new furnace or roof. For simplicity of exposition, our model does not provide for any such replacement.

DHS does not prohibit the use of the depreciation portion of a reimbursement payment for operating costs, but strongly recommends that it be funded, which means set it aside in a reserve. In fact, if an ICF/MR does not fund most, or

all, of its depreciation, its cash flow position will deteriorate each year into inevitable bankruptcy. Bankruptcy can be avoided however by adopting the policies reflected in the depreciation schedule of the attached table.

Depreciation Schedule.

In order to avoid financial disaster, an ICF/MR should exercise extreme caution before agreeing with DHS on a specific amount for depreciation. Whether the depreciation amount is enough to meet the mortgage installments depends on: (1) the interest rate charged by the bank for the mortgage relative to the rate earned by the depreciation fund, (2) the estimated salvage value of the home, (3) how long the DHS will pay the depreciation amount, and (4) how much of the reimbursement is put into the depreciation fund.

The model assumes that DHS and the ICF/MR agree that the estimated salvage value of the home is $35.933 in 30 years, or 360 months. This leaves $74,400 of its original value to be covered by depreciation allowances. Dividing $77,400 by 360 yields the $215 listed in each row of Column (5). The salvage value may seem low, but it is the most that the ICF/MR could agree to without incurring a cash deficit in a few years, as will be explained later.

The depreciation amounts are escrowed in a Depreciation Fund, bearing interest averaging 10%, from which the bank would withdraw each month an amount equal to the principal portion of the mortgage installment. Based on a mathematical formula, a calculator produced the amounts for the Depreciation Fund in Column (6). The result is an insignificant balance of $2,469 at the end of 240 months when the mortgage is scheduled to be liquidated.

Conclusion.

After the morrgage is paid off, it will receive $215 per month for depreciation for 10 more years. This it can feel free to use as it deems best -- to save, to expand, to buy another home, etc.

Figures in the table show how an ICF/MR gets into a cash bind if it does not fund its depreciation. In the 120th month the $248.96 principal portion of the installment is $34 more than the $215 depreciation, and the deficit becomes larger each succeeding month. This inevitability is what, understandably, concerns the banks.

The preceding analysis has attempted to show how the proposed tri-partite agreement would benefit an ICF/MR's financial health, both in the short-run and in the long-run. It is assumed, of course, that the ICF/MR obtains from DHS an equitable depreciation committment. I have gone into the problem in considerable detail because of the importance and difficulty in making the proper depreciation decision. It is a management decision. Providers must not simply ignore it by assuming that it will be handled by their accountant -- they should try to understand the issues and discuss them thoroughly with their accountant before settling with DHS.

It is our duty to inform the ICF/MRs and to help them obtain the cooperation of DHS and banks to solve this as well as their other critical financial problems.

| AMORTIZATION SCHEDULE | | | | | DEPRECIATION SCHEDULE | |
|---|---|---|---|---|---|---|
| MONTH | Installment | Interest | Principal | Total Principal | Monthly Depreciation | Depreciation Fund |
| 1 | $1119.27 | $1062.50 | $ 56.77 | $ 56.77 | $215 | $158.23 |
| 2 | " | 1061.79 | 57.48 | 114.25 | " | 317.17 |
| 3 | " | 1061.07 | 58.20 | 172.45 | " | 496.51 |
| 4 | " | 1060.34 | 58.93 | 231.38 | " | 636.58 |
| 5 | " | 1059.61 | 59.66 | 291.04 | " | 797.23 |
| 6 | " | 1058.86 | 60.41 | 351.45 | " | 958.46 |
| 7 | " | 1058.11 | 61.16 | 412.61 | " | 1,120.29 |
| 8 | " | 1057.34 | 61.93 | 474.54 | " | 1,282.70 |
| 9 | " | 1056.57 | 62.70 | 537.24 | " | 1,445.68 |
| 10 | " | 1055.78 | 63.49 | 600.73 | " | 1,609.24 |
| 11 | " | 1054.99 | 64.28 | 665.01 | " | 1,773.38 |
| 12 | " | 1054.19 | 65.08 | 730.09 | " | 1,978.00 |
| 24 | " | 1043.73 | 75.61 | 805.70 | " | 4,479.00 |
| 36 | " | 1031.58 | 87.69 | 893.39 | " | 6,247.00 |
| 48 | " | 1017.48 | 101.79 | 995.18 | " | 8,483.00 |
| 60 | " | 1001.12 | 110.15 | 1105.33 | " | 10,770.00 |
| 72 | " | 982.72 | 137.14 | 1242.47 | " | 13,084.00 |
| 84 | " | 975.02 | 144.25 | 1386.72 | " | 15.392.00 |
| 96 | " | 963.90 | 141.60 | 1528.32 | " | 17,655.00 |
| 108 | " | 941.10 | 164.10 | 1692.42 | " | 18,821.00 |
| 120 | " | 870.31 | 248.96 | 1941.38 | " | 21,824.00 |
| 132 | " | 830.29 | 288.98 | 2230.26 | " | 23,597.00 |
| 144 | " | 783.83 | 335.44 | 2565.80 | " | 25,029.00 |
| 156 | " | 729.91 | 389.36 | 2955.16 | " | 26,005.00 |
| 168 | " | 667.32 | 451.95 | 3407.11 | " | 26,381.00 |
| 180 | " | 594.96 | 524.60 | 3931.71 | " | 26,788.00 |
| 192 | " | 510.33 | 608.44 | 4540.65 | " | 25.090.00 |
| 204 | " | 412.44 | 708.63 | 5249.28 | " | 22,458.00 |
| 216 | " | 298.82 | 820.45 | 6069.73 | " | 11,311.00 |
| 228 | " | 166.93 | 952.34 | 7022.07 | " | 12,291.00 |
| 240 | " | 13.83 | 1105.44 | 8127.51 | " | 2,469.00 |

# STATE OF MAINE

A-29.

## Inter-Departmental Memorandum Date 4/30/81

To Lincoln Clark Dept.

From Ronald S. Welch, Director Dept. Bur. of Mental Retardation

Subject Memo "Financial Health of ICFs/MR"

"Financial health" is unquestionably an issue of major importance these days. Financial health, not only for the ICFs/MR, but, certainly for all of the services and programs serving Maine's mentally retarded citizens, has become, of necessity, a major focus of my attention.

The ICF/MR program has yielded dramatic increases in the operating revenues of those homes which have converted from the boarding care program. Most importantly, the residents of those homes have already manifested significant accomplishments in development and skills acquisition.

But, while the homes are not on the brink of financial disaster, nor, indeed, even headed that way, there are, without question, a number of structural and interpretive problems with the Principles of Reimbursement. Many of them could not have been anticipated during the implementation of this new program. Some of those issues have been resolved in the context of the DHS/BMR task force which is overseeing the implementation of the program. Some issues do remain unresolved. The timeline and forum for resolution, however, are contained in a memo from Jim Lewis (attached). I feel that the strategy which he has outlined is sound and realistic.

I do not want to appear to be putting these issues off, nor appear to be discounting their importance. I am, however, reaffirming my statement of priorities as discussed at our last meeting. Specifically, there are parts of the service delivery system which are in greater fiscal jeopardy than the ICFs/MR, especially considering President Reagan's desire to cut 25% of the funding for programs funded under Title XX of the Social Security Act.

The specific proposal which you have developed offers several interesting options which may have the basis for resolving some of the ICF/MR financing problems, especially as relates to the development of new homes. I am circulating a copy of the model to some of our "in-house" staff in order to determine its potential impact on the ICF/MR program, as well as on the medicaid budget.

I might add that with the proposed "cap" on medicaid, the need to be cognizant of the impact of such alternatives on the "MR medicaid dollar" is imperative.

Be that as it may, I will be able to comment on the proposal in more detail at our July meeting.

RSW:cc

cc: Commissioner Concannon
Karen Kingsley
Bob Foster

# Department of Human Services

A-30.

STATE HOUSE, AUGUSTA, MAINE

Date April 30, 1981

To Ronald Welch, Director, Bureau of Mental Retardation

From James H. Lewis, Director, Bureau of Medical Services

Subject ICF-MR Program Review

This is in follow-up to the meeting on April 2, 1981 of the ICF-MR Implementing Committee as regards the agenda item related to the ICF-MR Reimbursement Principles, Licensing and Certification Regulations, and Medical Assistance Manual policy and the feasibility of undertaking a review at this time.

As indicated at the time of that meeting, this is not a good time to undertake a review. First, we are still in the process of implementing the ICF/MR program as evidenced by the fact that several facilities remain in the conversion process. In addition, it was not until February 1981 that all ICF/MR's began billing in the MMIS and as such are still adjusting to the reimbursement system. Finally, a complete cycle for the survey and audit process will not be complete until each facility has participated for a full 12 month period.

As such a review should be planned at a time following sufficient operational experience. Accordingly, it is my suggestion that we reconsider this matter on October 1, 1981 to determine a time frame during which a review process will be of maximum value. During the interim I would recommend the forwarding to my attention of all comments, concerns, and criticisms related to ICF/MR program regulations, principles and policies. The Medicaid staff will continue to work closely with you and your staff to respond to the concerns articulated by provider and patient representatives.

JHL/cd

# United States District Court
## Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER

To: Kevin Concannon

From: L.C.

Subject: More Pineland placements to Foster Homes.

This is to give you a progress report following our discussion Tuesday regarding how to speed up the "communitization" of Pineland clients.

I met with Stan Butkus and was delighted that he shared my views on the desirability and feasibility of placing more clients in foster homes. He is preparing a short memo on procedure.

The essence is that he offered to undertake to find foster homes for ten Pineland clients within 90 days.

I talked with George Zitnay today who reacted enthusiastically to the idea of coming up with 10 candidates.

I suggested that they should be of two categories: (1) those who could attend existing day programs in the Augusta area and (2) some who are practically if not entirely bedridden requiring 24 hour attention. Presumably the foster homes taking the first category would not require supplemental reimbursement whereas for the second category supplemental reimbursement would be required to make the job attractive. As this supplement should save the State money over the present cost, it will be interesting to see what Stan can work out.

cc: Stan Butkus
Ron Welch
George Zitnay

# STATE OF MAINE



## Inter-Departmental Memorandum

Date April 1, 1981

To Lincoln Clark, Special Master — Dept. U. S. District Court, Portland

From Stan Butkus, Regional Administrator — Dept. Bureau of Mental Retardation, Region

Subject Foster Home Development

Enclosed is a belated overview of an experimental foster home development scheme for Pineland residents. It highlights the prerequisites for the approach.

I have begun discussion with Ron about the financial components, start up times and the like.

Stan

Enc:

SB/gr

## FOSTER HOME DEVELOPMENT OVERVIEW

PURPOSE: Purpose is to provide a more normal and less restrictive environment for 10 mentally retarded persons now resident at Pineland Center. Each home would serve 1-2 persons and be located in areas that would facilitate day programming as detailed in the IPP.

DEVELOPMENT CRITERIA: Foster home development will be geared to the identified needs of individual clients. Clients that require a specific type of day programming and/or specialized service will only be placed in geographic areas where that day programming or specialized service is available. The placement must also be consistent with the desires of the client or his/her guardian.

An experienced BMR staff person(s) will be assigned to develope foster homes and should be familiar with the resources in Region III, have a good relationship with Pineland staff and understand special education laws as they relate to school age persons. The foster home developer will provide a general orientation for the host family.

FOSTER PARENT CRITERIA: Foster parents skills/knowledge will focus on their ability to deal with persons who have unique and sometimes complex needs. The parents must be emotionally mature, stable and able to provide a living environment that is stimulating, nurturing, and consistent. The object of their activity is to provide basic care and assist the client to maximum development.

The role requires persons who can intelligently provide a sustaining home relationship with a mentally retarded person. It does not require specialized formal education, but a thoughful and planned approach to meeting the unique needs of persons who have

been residing at Pineland Center for many years. There must be willingness to work in partnership with BMR case services staff, day program staff, and any of a variety of therapeutic services specified in the I.P.P.

REGIONAL OFFICE SUPPORT: Once the foster home is established a mental retardation caseworker will be assigned to provide case management services. The caseworker will participate in the initial IDT developed at Pineland Center. In Region III the foster home experiment will require additional case work services on an ongoing basis, given the existing caseload average of 50 coupled crisis intervention role which each CSC now plays. The CSC will coordinate the provision of I.P.P. required therapeutic services. The Regional Supervisor will assign and monitor CSC involvement.

PINELAND CENTER: Pineland Center has agreed to screen and develope short summaries for the service needs and placement requirements of the ten persons in the experimental group. At this point 60 persons have been identified as potential placements. Doreen Doucette will coordinate operations from the Pineland Center.

In addition to the identification and coordination functions Pineland Center will develope the Individual Program Plan. The plan will include specific procedures for respite, readmission, and other specialized services that Pineland Center will provide.

In order to carefully document client progress the Adaptive Behavior Scale will be completed for each person leaving Pineland for a foster home placement. It will be particularly important to establish a behavioral baseline so that progress may be systematically monitored, especially as it might relate to maladaptive behaviors.

SERVICE AGREEMENTS/COMPENSATION: Services to be provided through foster home will be specified as part of the I.P.P. process and formalized through a service agreement. The service agreement will outline the responsibilities of the foster home, Region III and Pineland Center. It will be in addition to other agreements, i.e. Residential Services Agreements, that may be required by the Bureau.

Foster parents will be compensated in relation to the services and supervision they are required to provide. The payment will be negotiated on an individual case basis using existing specialized foster placement reimbursement rates as a guide.

# STATE OF MAINE



## Inter-Departmental Memorandum Date 4/30/81

To Lincoln Clark, Court Master Dept.

From Ronald S. Welch, Director BW Dept. Bur. of Mental Retardation

Subject Memos: "More Pineland Placements to Foster Homes (Concannon)"
"Foster Home Plan (Butkus)"

While the continuum of residential alternatives was certainly broadened with the advent of the ICF/MR program, its appearance on the scene begged the question of where are we going relative to still other alternatives. As you know, tne Stipulation Agreement commits us to expand the availability of independent living options for our clients. Foster care, likewise, is a viable alternative which, to date and for a number of legitimate reasons, has not blossomed to the extent that some of our clients need that service.

Recruitment, reimbursement, and support services are the keys to a successful foster home program. We have met with some success, through concerted recruitment campaigns, in attracting foster homes. Levinson Center has been notably effective in this regard. Support services can and will be coordinated by our regional office staff. Reimbursement, above and beyond that which is provided by the Department of Human Services, is, without question, the major challenge we face in implementing Stan's plan.

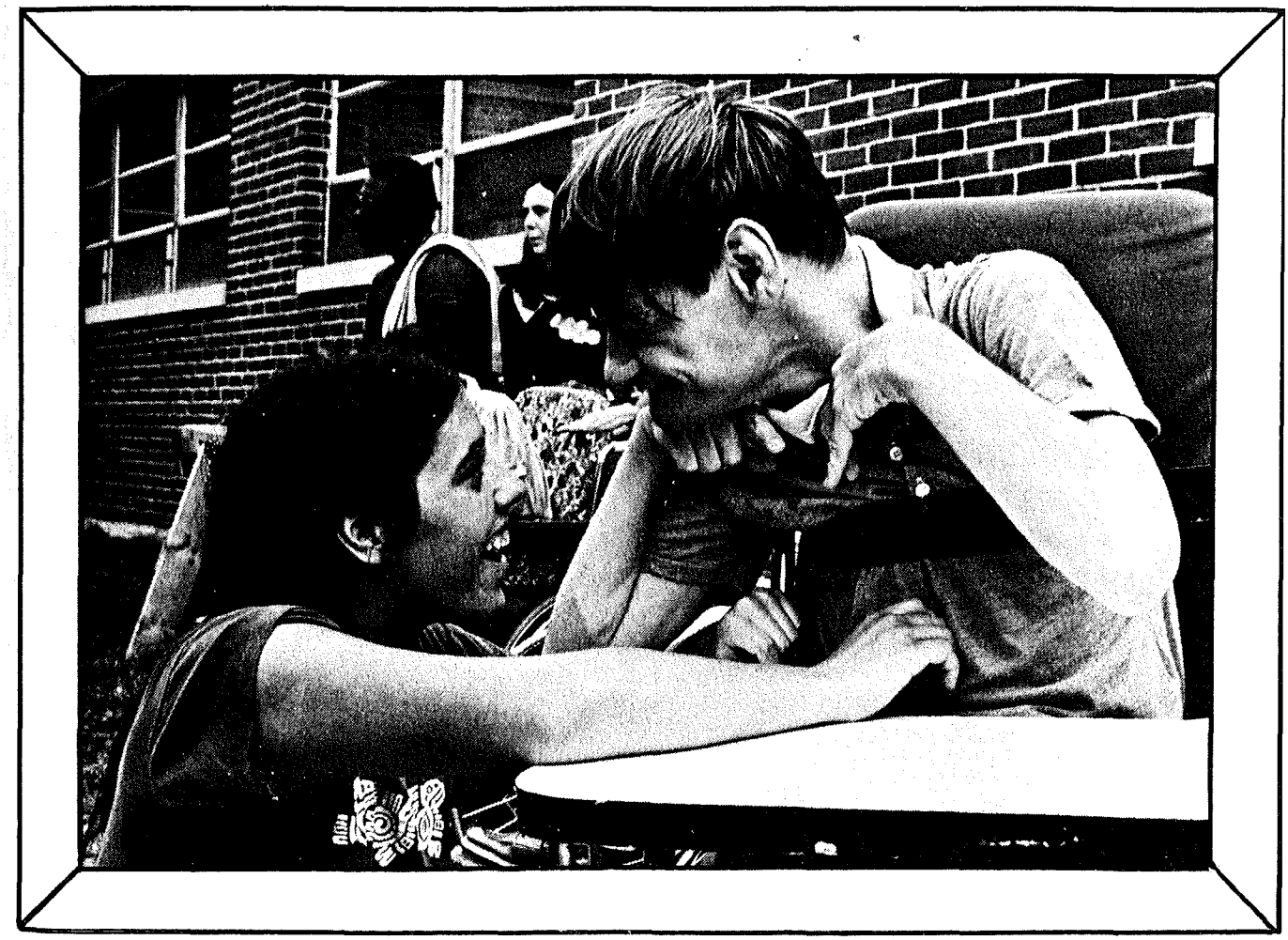
At the end of May the grant allocation plan for the Bureau will be developed. A top priority must be the financial stability and program continuation of the existing service delivery system. The introduction of this service would be a high second priority. For your information, it should be noted that the creation of an on-going subsidy program for foster care would be a new type of financial commitment for this Bureau. I will, therefore, review the program with Kevin relative to departmental policy and the AG relative to our statutory ability to finance such a program before moving ahead with implementation.

The bottom line, Lincoln, is that I will be able to provide you with an update at our June meeting.

RSW:cc

cc: Commissioner Concannon
Karen Kingsley
Stan Butkus

# THE MARTTI WUORI CASE-
# REPORT TO THE COURT



## Maine's Mentally Retarded
## Are Going Home

United States District Court
Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER

January 15, 1982

The Honorable Edward T. Gignoux
United States District Court
Portland, Maine 04112

Re: MARTTI WUORI, et al., Plaintiffs
v.
KEVIN CONCANNON, et al., Defendants

Dear Judge Gignoux:

Your discharge of Pineland Center has increased the momentum to reach compliance with the remainder of the Consent Decree. Seeing that discharge is attainable has stimulated the staff of the Bureau of Mental Retardation to find ways to transfer clients from institutions to community homes and to improve the quality of their care.

A question that has been frequently raised is when the defendants might be considered so fully in compliance with the Consent Decree as to warrant discharge by the Court. Excellent progress is being made on the fifteen Plans of Correction in the Stipulation Agreement of January 14, 1981. The major outstanding deficiency is the slow rate of transfer of Pineland residents to community homes.

A target date of July 1, 1982 was set a year ago. It could be hit. To do so, however, would require prompt, innovative and heroic efforts by the defendants and by the other State agencies upon whom the defendants are dependent for support. It is up to the defendants to win the support, which is only partly financial. Also needed are interpretations by the State of Federal regulations to assure the quality of care of Maine's mentally retarded citizens specified in the Consent Decree.

The following semi-annual report presents the details of the progress and obstacles.

Sincerely,

Lincoln Clark

Lincoln Clark

TABLE OF CONTENTS

PART I


| Section | | Page |
|---|---|---|
| INTRODUCTION | | I-7 |
| I | SUMMARY | I-7 |
| II | PLANS OF CORRECTION | I-12 |
| III | OBSERVATIONS | |
| | 1. Future of Pineland | I-14 |
| | 2. Create Therapeutic Foster Homes | I-18 |
| | 3. Lift the Moratorium on Boarding Homes | I-19 |
| | 4. Revise ICF/MR Regulations | I-21 |
| | 5. Consider Relative Placement Costs | I-21 |
| | 6. Don't Block Community Homes | I-22 |
| | 7. Count All Clients | I-24 |
| | 8. Let's Stop Discrimination | I-24 |
| | 9. Let the People Know | I-25 |
| | 10. Simplify the Certification Procedure | I-26 |
| | 11. Boost Day Programs | I-26 |
| | 12. Reduce Mental Retardation | I-27 |
| | 13. Serve the MR Offenders | I-28 |

PART II


| | | Page |
|---|---|---|
| PREFACE | | II-1 |
| Section | | |
| I | RESIDENTIAL FACILITIES FOR MENTALLY RETARDED CITIZENS | II-4 |
| II | FINANCIAL OBSTACLES TO THE DEVELOPMENT OF RESIDENTIAL FACILITIES | II-14 |
| III | COMPARATIVE COSTS OF RESIDENTIAL FACILITIES | II-24 |
| IV | PERSONAL CARE HOMES - AN ALTERNATIVE RESIDENTIAL FACILITY | II-31 |
| APPENDICES | | |
| A. | Estimated Cost and Funding Sources Per Resident for Residential and Program Services | II-33 |
| A-1 | Basis for Estimated Cost and Funding Sources | II-35 |
| B | Annual Costs and Funding sources for Current Placement of BMR Clients in Residential and Program Services | II-41 |
| C | Projected Annual Costs and Funding Sources for Alternative Placement of BMR Clients in Existing Residential and Program Services | II-42 |
| D | Projected Annual Costs and Funding Sources for Alternative Placement of BMR Clients Utilizing Personal Care Homes | II-43 |
| E | Comparative Annual Cost Sources Utilizing Personal Care Homes | II-44 |
| F. | Illustration of Capital Costs Associated with New Intermediate Care Facilities and Boarding Homes | II-45 |
| G | Position Paper - Administrative & Policy Planning Allowance | II-48 |
| H | Position Paper - Interest Expense and Related Reimbursement Issues | II-61 |
| I. | Bibliography | II-77 |

# Part I

## INTRODUCTION

This report has two major parts. Part I which deals with the progress and remaining problems, other than financial, impeding compliance with the Consent Decree of January 21, 1978, was written by the Office of the Special Master. It is based on correspondence and interviews with many persons throughout the State and especially, the advice and counsel of the contending parties. Essential and highly valued editorial assistance has been patiently provided by Elizabeth D. Porteous, Pauline S. Greason, Anne R. Clark and Anne R. Stanley.

Part II, dealing with financial problems, was commissioned by the Special Master. It was prepared by Michael T. McNeil and the staff of Berry, Dunn and McNeil. They have done a masterly job of assembling, organizing, analyzing and presenting a mass of data in a very short period of time.

## Section I SUMMARY

Over the past decade United States District Courts have issued twenty-two decrees to raise the quality of care for the mentally retarded. It is a great tribute to the State of Maine to be the first state in the Nation to win Court discharge of its largest institution for the mentally retarded, Pineland Center.

The Consent Decree of January 21, 1978 has two parts, the first relating to Pineland Center, the second to Community Standards. On September 18, 1981, the Court formally discharged Pineland Center. This report focuses on what remains to be done to achieve compliance with the second part of the Decree, Community Standards.

The most pressing task is to place in community homes the many residents of Pineland Center whose needs can be better served in the community.

The rate of transfer from Pineland to community homes has been slowing down since 1978. Placements declined from 64 in 1979, to 58 in 1980, to 36 through 1981, making a total of 158. While 285 openings in the community were created, they were not all available for Pineland clients; some were assigned to class and non-class members with higher priority needs who were in unsuitable homes. The State agreed in 1978 to establish 62 new openings every six months until the needs of the class are met. If this rate had been maintained, 410 openings would have been created by December 31, 1981. Since only 285 openings have been created since July 1978, Maine is about 125 openings behind schedule.

One possible break-through on the horizon is the establishment of therapeutic foster homes with personal care services allowable under Medicaid (see Observation #2). Such homes are deemed desirable for about 60 Pineland clients.

The State could provide more openings by lifting its moratorium on the expansion of boarding homes for the lesser mentally retarded (see Observation #3).

The severely retarded need community Intermediate Care Facilities for the Mentally Retarded. In addition to providing special services, they have the virtue for the Maine taxpayers of being 70 per cent financed by the Federal Government. There are now 22 ICF/MRs throughout the State, but none were started in 1981. Among the causes delaying their faster development are several regulations, principles and policies governing ICF/MRs which need to be revised so as to accord with standards in the Consent Decree and for which reimbursement is allowable under Federal regulations (see Observation #4).

A placement program that substantially reduces the backlog of

of Pineland residents who are ready to move to community homes would probably generate sufficient momentum to create openings for other clients who require more suitable accomodations than their present homes. This would free Pineland Center to perform an even more useful role as a short-term diagnosis and treatment facility (see Observation #1).

In order to meet the varying needs to Maine's mentally retarded, many different types of residential arrangements are required. A perennial problem is determining how many of each type and size should be provided. The resolution requires an analysis of the needs of the clients and a benefit-cost analysis of the alternative residential settings. (See Observation #5).

The status of the Plans of Correction called for by the Stipulation Agreement of January 14, 1981, is presented in Section II.

Community Integration. Community integration means becoming part of a community, not being excluded; associating with non-handicapped; having the same privileges as other citizens while focusing on community homes. Community housing is only the first step toward community integration.

A community integration program involves identifying the skills required for community living, assessing the client's skill levels, and designing a specific program for the client. Types of programs include: Fundamental Life Skills, Practical Life Skills, Work Activities, Personal and Social Adjustment, Work Adjustment Training, Vocational Skills and Sheltered Employment. Some clients also need support services: Psychological, Occupational, Physical and Speech Therapy.

The difficult task of providing community services requires the development and training of hundreds of experts in the community and the hearty cooperation of the general public. Existing community services should be used to the fullest: for instance, the community swimming pool at regular hours rather than at segregated hours; public transportation rather than a special bus; the public library rather than more books in clients' homes; regular church services rather than special services for handicapped people.

Although our long past history has been to segregate the mentally retarded in institutions, we recognize now that de-segregation is a better policy. Community resistance that has been delaying the establishment of community homes in a few Maine communities is being addressed by the Legislature (see Observation #6).

Number of Retarded. Nobody knows exactly how many of Maine's citizens are mentally retarded, where they all live, or how they are getting along. National studies of the incidence of mental retardation indicate that, depending on how mental retardation is defined, the number is somewhere between 15,000 and 30,000 in Maine. Presumably, most of Maine's retarded are living in their parents' homes, receiving the attention that their parents can provide. An undetermined number receive some services from the Bureau of Mental Retardation but are not registered as clients (see Observation #7). About 2,500 are registered clients; of these about 1,000 are class members.

Class members are defined as "all persons who were involuntarily confined residents of Pineland on or after July 3, 1975, or who were conditionally released from Pineland on or after July 3, 1975." There is a difference of opinion regarding whether persons admitted to and discharged from Pineland after June 3, 1975 are class members. This issue is important because the State is not obligated by the Decree to provide non-class members with the services mandated by the Decree. When resources are insufficient to treat all clients equally, non-class members receive inferior or delayed care. Even if discrimination on the basis of class status is legally defensible, it is morally wrong and contrary to the underlying purpose of the Consent Decree and of the State's statute governing the treatment of the mentally retarded which is designed to improve the quality of care for all Maine's retarded citizens. The Decree should be regarded as a means to this end; the end is not just to benefit pre-1975 residents of Pineland, although at the time of the suit the primary focus was on their needs.

The Decree sets standards to be met for class members. When the immediate demands for services exceed the available supply, the proper basis for any interim discrimination is "triage" -- allocating any scarce resource to those capable of deriving the most benefit from it.

It is hoped that the issue regarding class membership will soon be resolved. Also the State should re-emphasize and implement its policy to provide equal care to all clients without regard to their class status (see Observation #8).

Part III concludes with five other observations: #9 Let the People Know, #10 Simplify the Certification Procedure, #11 Boost Day Programs, #12 Reduce Mental Retardation, and #13 Serve the MR Offenders.

## Section II PLANS OF CORRECTION

Maine is on the threshold of significant improvements in its system of care for its mentally retarded, which makes it an exciting time for those who are involved in launching the Plans resulting from the Stipulation Agreement of January 14, 1981. Particularly innovative is a new Individual Program Plan (IPP) -- Plan (5). The IPP is a substantial refinement in the procedure to establish for each client his capabilities, program goals and means to achieve the goals. Correlated with the IPP is an improved procedure to yield quantitative data on the unmet residential, programmatic, and therapy needs of all the clients in the system -- Plan (9).

An independent expert is currently reviewing the implementation of six of these Plans: Plans (1), (2), (3), and (4), providing for the removal of all clients from Seven Elms, Willowcrest, and Hilltop Boarding Homes and removal or upgrading of the programming of all clients at Ward's Home, Pinkhams Home, Northland Manor, Bruce Haven, Tissue's, Hall Dale and Noyes Boarding Homes and for all clients in nursing homes; Plan (7) calling for assistance to the Consumers Advisory Board in providing trained correspondents to participate in Interdisciplinary Team meetings with all clients who cannot advocate on their own behalf; Plan (14) relating to training employees and service providers to meet Decree standards.

The remaining seven Plans, longer range but of critical importance, are briefly summarized below:

Plan (6) Evaluate statistically the Individual Program Plan and make appropriate revisions.

Status Will be initiated after Plan (5) is underway.

Plan (8) Evaluate and formulate plans to upgrade the programs at Bangor Regional Rehabilitation Center, Goodwill, Coastal Workshop, Pathways, Winthrop Work Activity Center, and Green Valley.

Status The report has been submitted and a plan is due February 15, 1982.

Plan (10) Formulate a plan to recruit, develop, and utilize State and national resources in the fields of occupational therapy, physical therapy, and speech therapy.

Status Due by February 1982.

Plan (11) Report quarterly on problems and progress regarding transportation, crisis intervention, family support, respite services, and community recreational opportunity.

Status These reports have been submitted on schedule.

Plan (12) Formulate a plan for tracking clients' needs and for resource development.

Status Awaits completion of Plans (9), (13), and (14).

Plan (13) Improve the monitoring systems for the quality of services delivered to clients, and to provide for prompt identification and correction of deficiencies.

Status Due in December, 1981.

Plan (15) Ascertain the most suitable community placement for each current Pineland resident for incorporation in the long-term community development plan of the Bureau of Mental Retardation.

Status The information has been compiled and is being included in Plan (9).

## Section III OBSERVATIONS

This section contains thirteen observations about possible actions to expedite the achievement of compliance with the Consent Decree.

### Observation #1 Future of Pineland

Three frequently asked questions about Pineland Center are: What has been the impact of its discharge from the Court's jurisdiction in September, 1981? Are clients better served in Pineland or a community home? When will Pineland clients be transferred to community homes?

Impact of Discharge. While under Court jurisdiction, the Pineland staff concentrated on reaching literal compliance with the provisions of the Consent Decree -- which they have achieved -- a big job well done. Being freed by the Court has boosted staff morale and more important, has stimulated healthy questioning and creativity. The staff is now asking questions like: How do we know this habilitation program is really right? How could we measure its effectiveness? Should we try this idea for a better program?

Continuing qualitative improvement in diagnosis and treatment is clearly predictable.

Pineland vs. Community Homes. Most observers contend that community homes are better than institutions for the clients, for the community, for the taxpayers -- and that is the mandate of the Consent Decree. This view stems from grim reports on the abysmal conditions that have existed in many institutions and from favorable reports on the progress of clients in community settings. Some observers feel, however, that the values of communitization have been exaggerated and that institutions do provide better treatment for some clients than available in many communities. Possibly these different views could be reconciled by making an operational distinction between treatment and care. Treatment means diagnosing a client's condition, developing and initiating an habilitation program. Care means meeting a client's daily needs and carrying out his prescribed habilitation programs in a home-like setting. Functionally then, institutions are good for short-term treatment, and community homes are better for long-term care.

In addition, continual research is needed on methods to prevent and treat mental retardation. Who should be assigned the task of research and development? It requires large resources and highly trained professionals, concentrated in one facility in order to stimulate the cross-fertilization of ideas. An institution, like Pineland, should be the manufacturer of new and better habilitation methods for which the community providers are the retailers.

At present Pineland staff are restrained from doing much pioneering by their heavy carry-over obligations to its long-term residents. As they leave, Pineland staff will be freer to delineate what should be done for the benefit of the community at large, that is, the specific kinds of treatment and research to conduct.[1]

Pineland should be regarded as a place to obtain the most advanced treatment available, not as a place for long-term incarceration. The general public does not fully appreciate its special capacities, but it is up to the Pineland staff to convince the community. As the long-term clients leave, Pineland can provide more backup support services to community providers and to families. Developing as a diagnostic and evaluation facility along with prescriptive program planning, outreach training and follow-up services, Pineland can contribute to the growth of services by community agencies. Its outpatient, training and treatment services will also increase the retention of mentally retarded citizens in community homes and with their families.

In order to meet the staffing needs of some community residences, a new approach to placements should be considered. A group of clients could be transferred along with familiar Pineland staff. The major obstacle in carrying out this simple concept is the disparity between staff

1. We expect medical research on problems of the general population to be applicable to the mentally retarded but often lose sight of the potential reciprocal benefit to the general population of research on the problems of the mentally retarded. For example, noting the high incidence of ulcers among the severe and profoundly retarded, Pineland doctors have been intensively studying 40 patients who are incapable of giving verbal responses to diagnostic questions. Identified symptoms include bleeding, anemia and vomiting. The detailed findings will be published shortly.

salaries and retirement benefits at Pineland and at community homes. The reluctance of Pineland staff to accept assignment to a community home at lower pay is understandable. Over the long-term, this situation is bound to be resolved, but in the meantime, they could be retained on Pineland's payroll. There are ample precedents for such outreach assignments, allowable under Federal cost reimbursement principles, in Connecticut, Michigan, New York and Rhode Island.

Transfer of Pineland Clients. The Consent Decree requires that all clients at Pineland Center whose needs can be better served in the community be transferred. Many of the 338 clients have been waiting a long time: 122 have been at Pineland over 25 years, 106 for 15-25 years, 66 for 5-15 years, 14 for 2-5 years and 24 for less than 2 years.

The questions about when and which Pineland clients should be transferred to community homes have received various answers over the past few years. The most recent answer comes from "Resident Profile Summary Charts" made by each client's Interdisciplinary Team. In arriving at a recommendation for placement, the IDT considers several factors: the preferred region of the state, the appropriate type of residence, the program needs and the support services required. They the IDT sets placement priorities which have been totalled in the table on the following page.

For administrative purposes the Bureau of Mental Retardation grouped the counties of the state into six regions: I (Aroostook), II (Hancock, Penobscot, Piscataquis, Washington), III (Kennebec, Somerset), IV (Androscoggin, Franklin, Oxford), V (Cumberland, York), VI (Knox, Lincoln, Sagadahoc, Waldo). The cells in the right hand column show the preferred regions for the placement of 314 clients. "State-wide" signifies that any region would be suitable, "Multiple" that more than one region would be satisfactory, and "P.C." that the client should remain at Pineland Center.

PLACEMENT PRIORITIES FOR PINELAND CLIENTS
by Region
(as of December 17, 1981)

| | Placement Priority | | | | | | |
|---|---|---|---|---|---|---|---|
| Region | #1 | #2 | #3 | #4 | #5 | #6 | Total |
| I | 0 | 1 | 1 | 3 | 1 | - | 6 |
| II | 0 | 0 | 4 | 5 | 5 | - | 14 |
| III | 1 | 1 | 2 | 4 | 4 | - | 12 |
| IV | 1 | 1 | 3 | 16 | 11 | - | 32 |
| V | 2 | 4 | 15 | 35 | 22 | - | 78 |
| VI | 0 | 0 | 1 | 3 | 2 | - | 6 |
| Statewide | 0 | 6 | 0 | 31 | 24 | - | 61 |
| Multiple | 1 | 6 | 4 | 29 | 17 | - | 57 |
| P.C. | 0 | 0 | 0 | 0 | 0 | 48 | 48 |
| Total | 5 | 19 | 30 | 126 | 86 | 48 | 314* |

* Information not yet completed for 24 clients.

The five clients assigned Priority #1 are not receiving appropriate residential and/or programming at Pineland and would be better served in the community. The 19 clients given Priority #2 are being well served but would make better progress in a community setting. The 30 clients with Priority #3 would benefit from a comparable residential and program setting nearer their families. The timing of transfer of the 126 given Priority #4 depends on the availability of a specific community setting that offers advantages over Pineland. Community placements of the 86 clients with Priority #5 are not presently scheduled because the complexity of their behavioral, medical and social conditions would preclude successful adjustment in community settings soon. The 46 clients with Priority #6 may remain indefinitely because it is believed that their complex residential/medical needs cannot be appropriately met in a community setting.

In summary, community settings with suitable residential, programming and support services should be made available for at least 276 Pineland clients (information is not yet complete on 24 clients) -- a big task and obligation. Of these 276 clients at least the 54 with Priorities #1, #2 and #3 could and should be placed in the community as soon as possible. Making these 54 placements by July, 1982, would seem realizable in view of the Decree provision that requires the creation of at least 62 openings every six months.

Observation #2 Create Therapeutic Foster Homes.

Maine's progress in caring for its mentally retarded citizens is worthy of becoming a model for other states to follow. There is danger, however, that inflation and austere funding policies may erode the progress that has been achieved. As one of the poorest states in the nation, Maine must continue to be creative in developing a range of service options to meet the unmet needs of the retarded.

A promising option that would cost about one-third as much as institutional placement is the therapeutic foster home -- a foster home with the capacity to provide specialized client services. Such development involves: (1) identification of mentally retarded persons currently in institutions and community ICF/MRs who could be appropriately placed in

therapeutic foster homes; (2) provision of personal care and day habilitation services for them; (3) training and certification of therapeutic foster home providers and (4) amendment of the Maine Medical Assistance Plan to provide personal care and habilitation services under Title XIX of the Social Security Act.

Many families would like to open their homes to mentally retarded persons. A recent single advertisement in two Augusta newspapers, inviting applicants, yielded 42 responses. Undoubtedly their motives are mixed -- a combination of desires to render a needed service and an interest in being paid (up to $200 per week per client). Clients have already been placed with nine of these families. It is estimated that an additional fifteen families will be approved for placements.

Benefits. A preliminary survey at Pineland Center identified 60 persons who might be suitably placed in therapeutic foster homes and a presently unknown additional number are transferable from community ICF/MRs. Therapautic foster homes represent a distinct improvement over traditional foster homes. Predictable benefits include: (1) improved program quality, (2) more spaces for more clients from Pineland Center and community ICF/MRs, (3) greater accountability of providers through training and certification, (4) better community integration of the mentally retarded, (5) more rapid development, as contrasted with the two to three years required to develop community ICF/MRs and, (6) homes and day programming for three persons at about the same cost as for one institutional or community ICF/MR placement.

Most of the details of the proposed program have already been worked out by the staff of the BMR. Launching of the program awaits the concurrence of the Department of Human Services.

Observation #3 Lift the Moratorium on Boarding Homes

Since no progress has been reported on the development of new group and boarding homes, the observation in my July report is repeated:

"In Maine, there are 3,478 licensed boarding home beds serving all population groups. Of these, about 600 beds are in sixty-eight group and boarding homes serving primarily the mentally retarded. They comprise the largest sector in Maine's network of facilities for the retarded, yet they have been the orphans of the network. Some existing group and boarding homes, including excellent ones, are on the verge of closing down because the State's reimbursement of their costs has not kept up with inflation.

The Office of the Special Master has received more grievances from group home providers than from any other category of residential providers.

The moratorium on the construction and expansion of group and boarding homes recently promulgated by the Maine Department of Human Services is a severe inhibiting factor for appropriate community placement of the mentally retarded.

Group homes are a necessary part of Maine's system for the retarded. They warrant support because: (1) Some Pineland clients are better qualified for admittance to group homes than to other types of community facilities; (2) Pineland has a waiting list of retarded who cannot be admitted until existing clients are discharged; and (3) group homes are desirable from a "cost-benefit" point of view.

The physical conditions of a group home are of less importance where a suitable day program is available and the residents are healthfully fed and clothed. Placement in a group home is generally preferable to institutionalization.

To assure the continued operation of existing group homes and to encourage the establishment of new ones to care for the mentally retarded, the State should revise its cost reimbursement schedule so that it relates to the quality and quantity of services provided. Reimbursement is now based essentially on just the number of residents in a home. There should be supplemental compensation to cover the cost of fulfilling the terms of service agreements between the State and the home. Many homes currently do provide habilitation services for their residents -- it would be advantageous to give them an incentive to do more. The service agreements would be monitored by case workers of the Bureau of Mental Retardation.

The Special Master feels he should express his opinion that there is a strong need for stepped up action on the part of all decision makers to examine and implement further resource development for group and boarding homes. A promising sign on the horizon is the recent legislative decision to form a special study group composed of members of the Joint Standing Committee on Health and Institutional Services and the Joint Standing Committee on Appropriations, Departmental and agency representatives, and consumers, to examine all aspects of group and boarding homes. The Bureau of Mental Retardation, Department of Mental Health and Mental Retardation has, and will continue to vigorously support this action.

There is reason to hope that this action will further the development and the fiscal stability of group and boarding homes in Maine. They are in sore need!"

Observation #4 Revise ICF/MR Regulations.

There are inconsistencies between the provisions of the Consent Decree and the program regulations, principles and practices governing the Intermediate Care Facilities for the Mentally Retarded which the State should rectify in consultation with the persons concerned with the enforcement of the Consent Decree.

The Department of Human Services by memorandum dated April 30, 1981, proposed that the regulations, principles and policies be reviewed by October 1, 1981. A letter soliciting the views of provider and patient representatives drafted November 9, 1981, has a time-table indicating that any appropriate revisions might be in effect by May 1, 1982. While this is progress, it seems agonizingly slow. The existing ICF/MRs are in excruciating need of revisions and the development of needed ICF/MRs is being seriously delayed.

Observation #5 Consider Relative Placement Costs.

An Interdisciplinary Team (IDT) has the responsibility for determining the best placement of a client. For a resident of Pineland, the team must first decide whether the resident should remain or move to a community residence. The main reasons for keeping a client at Pineland include strong client preference, behavorial problems, terminal illness and lack of a suitable community placement. Community placement is recommended when a less restrictive environment is thought to offer a better opportunity for personal development. If a case worker finds a suitable opening and if the IDT approves, the client is transferred. Relationship of Placement and Resource Development Policy. In some cases the choice of an appropriate type of placement for a client is clear-cut; in other cases the IDT may regard more than one type as appropriate and; sometimes, even when there are doubts about the needs of a client or the suitability of a particular opening, it may be deemed preferable to keep the resident at Pineland or Levinson Center.

The responsibility for creating openings is that of the resource developers in the BMR regional offices. Their guide as to types of openings to develop are IDT recommendations for client placements. This is in accordance with the traditional concept of the IDT as the fount whence all client programs should flow. It is suggested, however, that consideration be given to a modification whereby the IDT would identify the prospective clients for available openings which do meet their needs rather than "command" an opening for each particular client that may not be available. This switch in approach would not mean that resource developers could ignore IDT commands, but it would allow more leeway in allocating their budgets to develop various types of openings to increase their quantity.

An IDT, as a body of professionals, do not and should not let costs override other considerations in reaching placement decisions, but they could, without jeopardizing their professional integrity, make "benefit-cost" analyses of prospective placements. This entails reaching one of four conclusions: (1) that one prospective placement offers the same benefit as another, at lower cost; (2) that one prospective benefit offers greater benefits than another, at the same cost; (3) that one prospective placement offers greater benefits than another, at lower cost; or (4) that one prospective placement offers greater benefits than another, at greater costs.

The procedure to utilize the "benefit-cost" approach simply requires the resource developer to inform the IDT about the relative costs of available placements and the IDT to assess the possible benefits. A benefit-cost analysis would not result in an inferior placement for a client. The main effect would be to provide more beds for the money. The costs of alternative residential and program services are set forth in Part II of this report.

Observation #6 Don't Block Community Homes.

Applications for the establishment of community homes have been welcomed and routinely authorized by most communities, but in a few cases

local zoning ordinances have been used to block or delay their establishment. The State Legislature, now at work on this problem, may pass a law to establish a State-wide policy to insure non-discriminatory treatment by local governments, or it may continue to leave the matter to local communities.

The City of South Portland provides a good example of a positive approach. On April 22, 1981, after intensive study, hearings and reflection, the South Portland City Council unanimously approved an amendment to its zoning ordinance. First it formulated this definition of a community home:

> A dwelling in which there reside no more than six (6) unrelated persons (in addition to any persons related by blood, marriage or adoption) who are mentally retarded physically handicapped, or aged in need of routine care, and who also live as a single housekeeping unit, make the home their permanent residence, and provide conpensation for lodging, meals and care; as distinguished from a single family home, and hotel as defined herein.

Then this provision was added to make a special exception for community homes in all residential districts:

> Community homes shall be permitted unless in the judgment of the planning board there is documented evidence that one or more of the conditions listed in Sec. 27-47 of the Ordinance cannot be satisfactorily met.

It is permitted unless there is evidence that public safety standards cannot be met such as sewage disposal, electrical hazards, lack of running water, housing code violations or unhealthful living conditions.

Some localities are concerned that too many community homes on a particular street or in a particular block would make an abnormal environment. This objection could be dealt with by stipulating the maximum allowable density of community homes in a residential district.

It is the hope of the Office of the Special Master that the Legislature will act affirmatively to eliminate impediments to the establishment of group homes for Maine's mentally retarded citizens.

Observation #7 Count All Clients.

The Bureau of Mental Retardation does not receive full credit for all the persons it serves. In addition to the 1,000 class and 1,500 non-class members served regularly, the BMR provides occasional services for possibly two or three thousand more persons who do not want or need regular services. They may only seek information about Social Security benefits, or Medicaid, or the vacancies in residential facilities and day programs. In addition, an unrecorded large number of outpatients are served at Pineland. Since service takes up staff time, their work is understated. The practice should be instituted of recording all visits, service requested and provided, and time required. The information should be recorded on a standardized form in order to facilitate its aggregation in the central office. The value of the resulting data would, it appears, outweigh the nuisance of the additional paper work.

Although the recording of services to non-registered clients is a relatively minor issue, it raises a general problem. There is considerable variation in the way information is collected and recorded in the six regions of the BMR. While it is sound to decentralize the administration of central policies, conformity with established organizational principles requires that regional progress reports to the central office be standardized. Action is under way toward this end.

Observation #8 Lets Stop Discrimination.

The extent of discrimination in the community on the basis of class status appears to be diminishing month by month, but since the problem persists, the observation made in my July report is repeated:

> "In making transfers and providing services, Pineland and all community agencies serving class members must conform to the requirements of the Decree. The Special Master's responsibility is limited to class members, yet he feels obligated to voice his concern that class members receive preferential treatment in community placements, habilitation programs, and transportation arrangements. Of a total of about 2600 clients served by the Bureau of Mental Retardation, class members number only about 1000; morally, if not legally, preferential treatment of them is wrong. Although every employee of the BMR with whom the issue has been

discussed deplores this kind of discrimination, at times it has been condoned in order to achieve technical compliance with the Decree.[1] The Bureau of Mental Retardation should issue a forceful policy statement emphasizing that all of its clients shall receive equal treatment, in conformance with Decree standards, without regard to their Decree class. Such a statement might forestall the possibility of a petition to the Court to bring about equal treatment for all clients."

Observation #9 Let the People Know.

The public is generally unaware of the dedicated, conscientious and creative efforts of hundreds of providers and professional staff around the State and of the staff of the Bureau of Mental Retardation. Public awareness is prerequisite for public support. The public has to be reminded constantly of its obligation to help those who can't help themselves.

Maine can rightly be proud of the quantity and quality of the residential, program and therapeutic services which have been developed over the past few years. The addition of each new facility, however, decreases the size of the pool of interested potential providers. The potential exists, the interest has to be developed.

Community homes and day programs for the mentally retarded require more professional workers and volunteers.

A continual need is the public's support to identify work opportunities for graduates of sheltered workships. They can be productive workers in many kind of jobs.

The public wants to know about the causes of mental retardation, remedial measures, and what can be done to reduce the risks.

---

1. Here is an example: The Decree stipulates that "no more than three clients shall occupy one bedroom. No facility developed after January 1, 1978 shall have more than two clients in any bedroom."
   Technical compliance has been achieved by removing class members from rooms with four beds with their assignment to non-class members. This has been condoned on the grounds that, because of the shortage of open beds, it takes care of one more client.

Just as the mentally retarded must learn to adapt to the community, the community must learn to accept and help their integration into the community.

Steps have recently been taken by the BMR central office to strengthen its public relations program, but more needs to be done in the regions, where people are. Good organizational practice requires the appointment of a public relations coordinator, which some regional administrators have already done. The public relations function will not be effectively carried out if it is only subsumed by the regional administrators as one of their general responsibilities.

Observation #10 Simplify the Certification Procedure.

As observed in my July report, the procedure for admission to Pineland Center and Levinson Center should be simplified. An amendment of the Statute governing admissions has been drafted and submitted to the Legislative Committee for its consideration. It is difficult to reach agreement on a procedure that is more efficient than the existing one, which at the same time fully protects the rights of the clients.

It is believed, however, that the remaining issues will soon be reconciled.

Observation #11 Boost Day Programs.

All capable clients in community homes are expected to attend community day programs or sheltered workshops four hours each week day. The providers are typically non-profit organizations with insufficient resources to absorb all of the clients who are scheduled for community placement. Their funding comes from both State and private sources. A basic financial policy question is how much should come from each source. Should the State supplement private contributions or should private contributions supplement government grants? At present, providers who seek grants from State agencies are required to submit budgets showing all their sources of income. Many providers believe that the more they raise locally, the less they receive from the BMR, but the BMR denies that this happens.

The State has established the standards for day programs; these are maximum standards. If minimum standards were identified, however, an appropriate division of financial responsibility would have the State supply sufficient funds to meet the State's minimum standards and for the day programs to raise funds from the community to provide services above the minimum. Thus a community could aim to provide as superior services for its retarded as it desires.

As another approach to encourage high quality of service, the BMR is proposing to conduct a contest with ten $2,000 cash prizes for the day program providers who develop and carry out the most effective community fund raising programs in 1982.

Observation #12 Reduce Mental Retardation.

If all of the options were carried out, it has been estimated that the incidence of mental retardation could be reduced by about 50 per cent. Early and continuing pre-natal care is probably the single most important preventive measure, and should be encouraged especially for pregnant women in the high-risk age groups of under 20 and over 35. Expectant mothers of all ages should be informed about the possible dangers to the unborn child of excessive drinking and smoking during pregnancy.

Doctors now can anticipate problems which once were faced only after birth. Pre-conception tests can reveal carriers of Tay-Sachs disease, which causes a baby to degenerate both physically and mentally, and usually to die before the age of three. Amniocentesis, in which cells are drawn from the amniotic fluid, permits analysis of chromosome deficiencies that account for a hundred or more disabling conditions, including Down's Syndrome.

A very recent discovery, by the New York State Institute for Basic Research in Developmental Disabilities, enables pre-natal identification of "fragile X" syndrome, a condition that often affects males. It is hoped that some state institution in Maine, perhaps Pineland, may be charged with the responsibility to conduct similar research here.

There are other weapons for combatting retardation. analysis of a single drop of blood from an infant can lead to prevention of numerous diseases; the "Lead Based Paint, Lead Poisoning Control Act" has stopped the manufacture of paints containing lead; a vaccine immunizes children against German Measles - a serious disease if contracted by the mother in her first trimester of pregnancy; RH problems can now be solved by amniocentesis and through immediate exchange transfusions after the birth of the child.

Maine, like many rural states, has a special problem with many children who, because of their poor environment, are slightly retarded. This causes them to fall progressively behind in school. Often they are just slow learners who, if given an early boost, would be able to keep up, reach their potential and become productive taxpayers. More services are needed to educate rural parents and to provide early screening, diagnosis and special programming for their children.

The Legislature's Judiciary Committee is considering a bill that would allow a mentally retarded person to request sterilization. It would also permit, under strict safeguards, the sterilization of those who are so severely retarded that they are unable to make the decision for themselves. In every case, convincing evidence must be presented to the court that the procedure is in the patient's best interests. The bill would provide that the most reversible sterilization techniques be used and that a panel review sterilization approvals yearly to assure that the law is not misused.

Observation #13 Serve the MR Offenders.

An often ignored group of the mentally retarded is "MR Offenders" who have been committed to correctional institutions. Because criminals are not tested for mental retardation, we do not know how many there are in Maine, but it is estimated to be at least 40. Their judicial commitment causes them to lose their civil rights but not their Decree rights. They are not receiving the habilitation services that they ought to have.

MR offenders are not being offered habilitation programs because they are distributed among several correctional institutions. Servicing them where they are would be very complex and expensive. Concentrating them in a single correctional institution would simplify the problem, with program staff and program services provided by Pineland Center staff or the Bureau of Mental Retardation.

Another alternative that merits exploration would be the creation of a small secure facility at Pineland Center. The Department of Corrections would provide the security staff, and Pineland Center would provide programs and support services.

Implementation of a program for the MR offender will require careful planning and the cooperation of the Departments of Correction, Human Services, and Mental Health and Mental Retardation. Statutory changes will also have to be considered. It is worthwhile to plan for this special group, to try to salvage some of them to lead useful lives after they are released back into the community.

# PART II

# RESIDENTIAL FACILITIES FOR MAINE'S MENTALLY RETARDED CITIZENS

## ANALYSIS OF THE COST OF CARE AND RELATED INFORMATION

BERRY, DUNN & McNEIL / Certified Public Accountants
96 Harlow Street / Bangor, Maine 04401 / (207) 942-6343

Lincoln H. Clark, Special Master
Portland, Maine 04101

We have prepared the accompanying report at your request containing analyses of operating costs of residential facilities which serve Maine's mentally retarded citizens. The report is based on financial, statistical and other information provided by representatives of the Maine Bureau of Mental Retardation, the Maine Department of Human Services, and other interested parties. The comments and conclusions contained in the report are predicated on the information provided to us and the specific assumptions used to analyze this information and are meaningful only when considered in conjunction with the assumptions stated in the report.

December 18, 1981

Berry Dunn & McNeil

# PREFACE

## Purpose and Scope of Report

As a result of the Consent Decree (Decree), the Maine Bureau of Mental Retardation (BMR) was charged with the primary responsibility to improve conditions at Pineland Center and to provide "habilitation" and "communitization" of its clients. This objective was to be achieved by providing the appropriate amount of training and education to fit the needs and capabilities of each mentally retarded citizen, and by providing an opportunity for each mentally retarded citizen to live in the least restrictive environment commensurate with their personal and health care needs. The Decree requires deinstitutionalization. The procedures developed to accomplish this may result in the establishment of a comprehensive system of evaluation, placement, training and habilitation that will minimize the institutional care for future generations of mentally retarded citizens.

The key to successful accomplishment of deinstitutionalization is the Interdisciplinary Team (IDT), a group of qualified medical, social and psychiatric professionals. They evaluate each mentally retarded individual to determine their needs and capabilities and establish a program consistent with the level of communitization and habilitation suitable for each individual.

Once each individual's needs are determined, BMR resource development workers attempt to place the individual in the residential environment consistent with the individual's prescribed program. There are various types of residential facilities currently available, each with a financial cost associated with the type of care offered. In some cases, more than one type of residential environment may be suitable for an individual.

The Special Master appointed by the Court to oversee the implementation of the terms of the Decree considers the relative cost of each alternative residential facility to be an integral part of the information necessary to formulate economically efficient policies concerning the placement of mentally retarded individuals subsequent to the determination of appropriate individual

program needs. The purpose of this report is to summarize and analyze the current information related to the comparative cost of alternative residential facilities for mentally retarded citizens.

No conclusions should be formulated from this report concerning the quality or preferability of one type of residential care in comparison to other alternatives. Such judgements require the initial evaluation and determination of an individual's program needs which are beyond the scope of this report.

Acknowledgements

We acknowledge the valued assistance and cooperation of the representatives of the Maine Department of Human Services (Department) and BMR who provided essential input for this report, particularly Robert Foster, Stanley Butkus, and Rob Jones of BMR, and Earl F. Getchell and John Wakefield of the Department.

Summary

The general conclusions formulated from the information analyzed in the remainder of this report include:

- Successful deinstitutionalization requires the development of the residential facilities to accomodate the defined program needs of Maine's mentally retarded citizens.

- The highest cost of care per resident is associated with residential facilities that require special purpose buildings (Section II).

- Reimbursement methods used to compensate providers for the care rendered to government program beneficiaries are not conducive to attracting either capital to expand the available residential facilities or the qualified people to render care to the mentally retarded (Section II).

- The development of "personal care homes" as an alternative residential facility for some mentally retarded citizens, and the use of Title XIX as a funding vehicle, could reduce the State's cost by more than $1,000,000 compared to the use of alternative available facilities (Section III and Appendix E).

# PART II

## SECTION I

## RESIDENTIAL FACILITIES FOR MENTALLY RETARDED CITIZENS

Residential facilities available to the mentally retarded are destinguished by comprehensiveness and intensity of health, social and habilitation services provided to residents. The types of residences included in this report are:

- o Residential Treatment Facilities
- o Pineland Center
- o Intermediate Care Facilities for the Mentally Retarded
- o Intermediate Nursing Care Facilities
- o Boarding Homes (Group Homes)
- o Foster Homes
- o Family Care
- o Supervised Living
- o Independent Living
- o Food and Lodging Accomodations
- o Personal Care Homes

The general characteristics of each of these facilities, together with the estimated average annual cost per resident and the primary sources of funding associated with each, are described in the remainder of this section. The methods and assumptions used to estimate the annual cost per resident are detailed in Section II of this report and Appendices A and A-1.

## RESIDENTIAL TREATMENT FACILITIES

Residential Treatment Facilities are primarily designed to provide therapeutically planned group living situations within which educational, recreational, medical, social and psychiatric approaches are integrated for individuals whose problems preclude a less restrictive level of mental health services. These facilities normally serve emotionally handicapped individuals, but also occasionally serve mentally retarded citizens. Individuals included in this category for purposes of our model population in Appendix B include some utilizing privately owned and operated facilities as well as some at Pineland, Bangor Mental Health Institute and Augusta Mental Health Institute. The level of individual programs offered require specialized staff and physical structures designed for the needs of the residents.

The estimated average annual cost per resident range from $40,000 for privately operated institutions to $30,000 for some State operated facilities. We have used an estimated average annual cost per resident of $33,757. Generally, the cost for each individual using privately operated facilities is determined by negotiations between BMR and the provider of the care dependent upon each individual's program needs. The funding is normally all State appropriations. The funding of the cost associated with the use of State operated facilities is partially funded by Federal sources. There are currently 60 clients of BMR utilizing this type of facility. An average of 24% of the annual estimated average cost per resdient for these 60 individuals is funded from Federal sources, and 76% from State sources.

PINELAND CENTER

Pineland Center is a physical complex with the capacity to provide most municipal services and functions autonomously. It is owned and operated by the State of Maine under the direction of BMR. It provides the most comprehensive combination of health, educational, social, psychiatric, habilitation and other ancillary services offered in a single location to Maine's mentally retarded citizens. There were approximately 1,500 residents at Pineland in 1955. This has now been reduced to approximately 350 residents. The facility serves some of the most severely developmentally disabled individuals in addition to others less severely handicapped who may reside at Pineland only because an appropriate, less institutionalized alternative residence is not available.

In 1980 the Center was licensed for approximately 400 Intermediate Care beds for the mentally retarded in conformity with State of Maine licensing regulations. The facility has been segregated from other Intermediate Care Facilities for the Mentally Retarded (ICF/MR), for purposes of this report because of its unique physical plant, the comprehensive programs offered which are not duplicated by other ICF/MRs, and the State ownership of the facility which necessitates all costs not absorbed by other available sources be borne by State appropriations.

The annual average cost of care per resident is estimated to be $36,883. The funding of these costs is primarily from Medicaid Title XIX funds, (70% Federal and 30% State appropriations), and a variety of other State appropriations for costs that are not covered by the Title XIX program.

## INTERMEDIATE CARE FACILITIES

Intermediate Care Facilities consist of those specifically licensed for the mentally retarded (ICF/MR) and intermediate nursing care facilities (ICF) which serve primarily the aged. They are normally single structures designed for the purposes of rendering medical care as well as satisfying residential and social needs of residents. They are licensed under provisions of State licensing regulations.

The ICF/MR is a relatively new form of facility in Maine. Their development was stimulated by the Decree as a smaller institutional alternative to Pineland. Their creation was also in response to the deficits incurred in the State Boarding Care program in which several current ICF/MRs were former participants. There are currently 22 ICF/MR facilities ranging in capacity from 6 to 35 beds. They provide approximately 260 licensed beds. Most of these facilities were licensed during 1981. The new facilities constructed or in the process of construction during the last two years have not exceeded a capacity of 20 licensed beds. All except three of the 22 facilities are non-profit organizations. Substantially all residents of these facilities are beneficiaries of the Title XIX program. Most residents participate in day care or habilitation programs outside the facility.

There are approximately 140 ICFs that provide general intermediate nursing care to the aged. A few of these are capable of providing care to mentally retarded individuals who do not require concentrated supervision for their developmental disabilities. The facilities are generally larger than ICF/MRs and most facilities are proprietary instead of non-profit organizations. Approximately 80% of all residents in these facilities are beneficiaries of the Title XIX program with the remainder being self-supported or family supported. Generally, mentally retarded residents of these facilities do not participate in day care or habilitation programs.

The "allowable cost" of care rendered by ICF/MRs and ICFs to Medicaid beneficiaries is reimbursed by the Title XIX program. Costs which are not "allowable" for the Title XIX program must be borne by the facility from prior years reserves, donations, or profits earned from self-pay residents.

Effective July 1, 1980, the Department implemented "Principles of Reimbursement for Intermediate Care Facilities for Mentally Retarded in the State of Maine", (ICF/MR Principles) which define the specific costs of operations related to an ICF/MR allowable for reimbursement under the Title XIX program. The average annual allowable cost of care per resident covered by Title XIX is estimated to be $28,440. This includes a maximum annual allowable cost of $4,575 per resident for day care and habilitation programs. Allowable costs include both "routine service" and "capital" costs. Title XIX funds are currently provided approximately 70% by the Federal government and 30% by State matching funds.

The allowable cost of care subject to Title XIX reimbursement for ICF facilities is defined by the "Principles of Reimbursement for Long Term Care Facilities" (ICF Principles) promulgated by the Department effective January 1, 1978. The average annual allowable cost per resident for ICF care is estimated to be $12,545. The ICF Principles also provide for reimbursement of all allowable "routine service" and "capital" costs. Funding of the costs for Title XIX ICF beneficiaries is the same as the ICF/MR costs. Individuals in ICFs do not normally participate in off-site day care or habilitation programs, and no cost incurred for such services are allowed in the ICF Principles.

BOARDING HOMES (GROUP HOMES)

There are approximately 3,000 licensed boarding care beds in Maine with more than 500 of these beds serving primarily the mentally retarded. Facilities range in size from 4 to 45 licensed beds with most facilities having a capacity of 6 residents. For the purpose of this report, "Group Homes" and "Boarding Homes" are considered to be the same type of facility. These facilities generally are single structures which previously served as a family residence before conversion to a boarding care facility. These operations are both proprietary and non-profit. They provide personal care, supervision and training to those who generally do not have severe health or developmental problems. The residential setting is normally less institutionalized than Residential Treatment Facilities, Pineland, or Intermediate Care Facilities. Most residents participate in day care programs outside the facility.

Boarding homes in Maine are classified as those on the "cost reimbursement system" and those on the "flat rate system" for the payment for care rendered to the State program beneficiaries.

There are in excess of 60 facilities offering services primarily to the mentally retarded which participate in the "cost reimbursement system." Allowable costs of care for residents in these facilities are defined by the "Principles of Reimbursement for Boarding Care Facilities" implemented by the Department effective July 1, 1978. The total estimated annual allowable cost of care per resident is $10,827 including annual costs of $4,575 per resident for off-site day care and habilitation programs. Costs incurred and not covered by the program must be borne by the provider.

Although these Principles provide for the reimbursement of both allowable "routine service" and "capital" costs, they also accord the Commissioner of the Department of Human Services the authority to establish a ceiling on the reimbursement for otherwise allowable "routine service costs".

"Routine service costs" include all operating costs other than "capital costs." Capital costs consist of:

- Depreciation on buildings, fixed equipment and land improvements, and amortization of leasehold improvements.
- Interest on long term debt.
- Real estate taxes and fire insurance premiums.
- Return on equity capital of proprietary providers.
- Lease payments attributable to the above items.

Allowable capital costs are reimbursed 100%. Effective since July 1, 1981, the ceiling on the reimbursement of allowable routine service costs has been $515 per month per resident. There is a provision in the Principles for a "special circumstance allowance" which provides for payment of allowable costs in excess of the ceiling. Prior Department approval must be obtained before these costs are incurred, and approval is generally limited to the compensation of staff members in excess of minimum staffing requirements that may be necessary to accomodate the specific needs of the residents. Approximately 25 facilities currently receive special circumstance allowances which range from $20 per month per resident to $380 per month per resident. Estimated annual costs for these allowances is a minimum of $170,000. The funding for these allowances is all provided by State appropriations. The funding for the remainder of the allowable cost of care, exclusive of the cost of day care and habilitation programs, is also provided by State appropriations, except for Supplemental Security Income payments by the Federal government in the amount of $225 per month per resident. The annual estimated cost of day care and habilitation programs of $4,575 is funded 32% from Federal sources and 68% from State appropriations.

Boarding homes which are reimbursed for resident care on a "flat rate basis" are paid a fixed sum of $335 per month per resident. There is no central source of information on the actual cost of operations for these facilities since they are not required to submit financial data to government agencies. The $335 per month payment is composed of $225 Federal Supplemental Security Income, and $110 of State appropriations. The annual estimated cost for day care and habilitation programs of $4,575 is funded as described previously. The total estimated average annual cost per resident is $8,595.

FOSTER HOMES

Foster homes generally consist of licensed or approved families who assume the responsibility for the care of non-family mentally retarded persons in their homes. This environment provides the individual with experiences in a family setting and an opportunity to participate in community life. Normally, there are no more than two residents per foster home. The atmosphere of the foster home is less institutionalized than the type of facilities previously discussed. Care is provided in existing family residences with no special facilities required.

Providers of foster home care are normally paid a fixed sum of $272 per month for each resident in their home. This is comprised of $225 Federal Supplemental Security Income, and $47 from State appropriations. In addition, however, there are currently 38 individuals residing in foster homes who have special needs. Individual supplemental contracts have been negotiated by BMR with the foster home care providers for supplemental payments amounting to approximately $112,000 annually paid from State appropriations. Most of the residents of foster homes also participate in day care and habilitation programs outside the foster homes with an estimated annual cost per resident of $4,575 funded as described previously. The total estimated average annual cost of care per resident is $8,430.

SUPERVISED LIVING

Supervised living situations utilize existing apartment accomodations for the residents, a group of whom are usually located in the same building. A person providing professional staff support resides in this area to render ongoing training in housekeeping, personal hygiene, budgeting, nutrition and utilization of community services. Most of these individuals participate in outside day care and habilitation programs.

The cost for this type of residence consists of the amount paid to the resident in the form of Federal Supplemental Security Income of $225 per month and supplement of $16 paid from State appropriations. The day care and habilitaion cost of $4,575 annually per resident is funded by Federal and State sources as described previously. The professional supervisory staff are each capable of monitoring approximately 6 individuals residing in a supervising living atmosphere. The average cost per resident is approximately $2,500 per year for these personnel which is funded entirely by State appropriations. The total estimated average annual cost per resident is $9,967.

INDEPENDENT LIVING

Independent living is similar to supervised living, except that the individual participating in an independent living atmosphere does not require daily supervision. They function primarily on their own with periodic contact from their case worker.

Funding for independent living is identical to the supervised living, except there is no cost for professional staff supervisors. The total estimated annual cost of $7,467 per resident includes the cost of day care and habilitation programs.

FAMILY CARE

The largest number of mentally retarded citizens who are clients of BMR currently reside with their families or relatives in existing family homes. Most of these individuals participate in a day care and habilitation program.

Generally all government funding for family care is provided by Supplemental Security Income, although this is not available for all residents in this category. The cost of funding of day care and habilitation programs is as described previously. The estimated annual cost per resident is $6,375.

FOOD & LODGING

Food and lodging facilities are utilized by individuals functioning almost completely independently who reside in existing facilities of their own choosing which provide common living and dining areas. No residential programming is offered, and the facilities are not established to primarily serve mentally retarded individuals. Residents normally participate in off-site day care and habilitation programs. Existing facilities are utilized for those residents in this category.

The cost associated with food and lodging facilities is the $225 per month provided by Federal Supplemental Security Income and an additional supplement of $16 provided by State appropriations. The cost and financing of day care and habilitation programs is as described previously. The total estimated average annual cost per resident is estimated to be the same as independent living, $7,467.

PERSONAL CARE HOMES

This form of residence is a new concept in the State which is still in the development stage. Personal care services are generally those geared to the support and care necessary for developmentally disabled persons to maintain or enhance his or her health conditions, safety, and self preservation. They are generally designed to help the developmentally disabled individual maintain

and improve his or her physical and behavorial conditions within a humane living community environment. It is envisioned that this type of facility will provide care that may now be rendered to some whose program needs mandate placement in an ICF/MR, boarding care facility, or foster home requiring the payment of a special circumstance allowance to the foster home provider. The physical structure and atmosphere would be similar to a foster home or small boarding home (group home). Providers of this care would use their own residences and would receive special training to address the needs of the residents. Some current group homes and foster homes would qualify for classification as personal care homes. This type of facility may provide a vehicle to "normalize" the residential environment for some individuals whose only current alternative is a more institutionalized setting. Creation of these facilities also circumvents some of the financial obstacles confronting the maintenance and expansion of some of the current types of residential facilities.

It is estimated that the total cost of care per resident would be comprised of the Federal Supplemental Security Income payment of $225 per month ($2,700 annually), plus approximately $4,000 per year for personal care needs, and $4,575 per year for off-site day care and habilitation programs. The cost of both personal care needs and day care and habilitation programs may qualify for Title XIX funding. A waiver must be obtained from the Federal Health Care Financing Administration (HCFA). If this were accomplished the $8,575 of cost for these services will be funded 70% by the Federal government and 30% from State appropriations.

PART II

SECTION II

# FINANCIAL OBSTACLES TO THE DEVELOPMENT OF RESIDENTIAL FACILITIES

Accomplishing deinstitutionalization mandated by the Decree requires the availability of an adequate supply of alternative residences and habilitation programs to accomodate the individual program needs of the mentally retarded citizens. Several economic and regulatory factors threaten the financial stability of some current facilities and hamper the development of additional resources.

- o Escalation of capital costs associated with the construction and renovation of physical structures required for some facilities.
- o Diminishing sources of financing for construction, renovation and working capital needs.
- o Lack of financial incentive in the methods of payment for care rendered to beneficiaries of government Medicaid and Boarding Care programs.
- o The State's moritorium on new boarding care beds.

## CAPITAL COSTS

### Intermediate Care Facilities

The development of most new ICF/MRs and all ICF facilities require the construction of new buildings to comply with existing licensing and Life Safety Code regulations. New facilities require approval by the Department in accordance with the Maine Certificate of Need Act of 1978. Based on recent applications submitted to the Department's Project Review Division of the Bureau of Health Planning and Development, the cost of construction for a 20 bed ICF/MR is approximately $40,000 per bed, and the cost of construction for an ICF with a capacity of 50 to 100 beds is approximately $25,000 per bed. A significant portion of the cost of care for residents

of these new facilities is the capital cost, primarily building depreciation expense and interest expense on the debt incurred for construction. This component of the annual cost of care has increased dramatically during the last ten years due to increasing construction costs. During the last eighteen months it has been accelerated even more dramatically by the increase in interest rates.

Appendix F illustrates the impact of the capital costs that must be incurred to construct new intermediate care facilities. Annual interest and depreciation expense for a 20 bed ICF/MR are estimated to be $7,942 per resident and $4,964 per resident for a 50 bed ICF. These capital costs are in excess of 25% of the total annual average costs per resident for facilities currently operating (Appendix A). Since substantially all mentally retarded residents of these facilities are beneficiaries of the Medicaid program, these capital costs have a significant impact on the required Federal and State funds. This significantly restricts the amount of expansion that can be absorbed within the funding constraints currently imposed or threatened on the Medicaid program by the Federal administration.

Boarding Care Facilities

Boarding care facilities for the mentally retarded are normally created by the renovation of existing structures previously utilized as single family residences. Some small ICF/MRs can also be created in this manner. Funds are generally required to acquire the residence and renovate the physical structure to comply with licensing and Life Safety Code regulations. Appendix F illustrates the annual capital cost associated with a new boarding home developed in this manner.

The estimated annual interest and depreciation expense of $2,252 per resident for the illustrated 12 bed facility is more than 20% of the current average annual cost per resident for a boarding facility participating in the cost reimbursement program. Since most residents of these facilities are beneficiaries of the State Boarding Care program, the capital costs associated with the creation of new facilities places an increased financial burden on the boarding home appropriations which already suffer deficits.

Other Facilities

Foster homes, supervised living accomodations, independent living accomodations, food and lodging and family residences do not generally require the creation of separate physical facilities specifically for the mentally retarded; they utilize existing homes or apartments. None of the government payments to providers or residents in these residential environments are for capital costs. Therefore, these types of residences have lower average annual costs per resident compared to the special purpose facilities.

## FINANCING CONSTRAINTS

The availability of financing for new facilities and major renovations has diminished significantly due to reductions in Federal programs and general economic conditions. Low interest bearing long term loans were available for non-profit organizations through the Farmer's Home Administration and other government agencies for the construction of new ICF/MR facilities and intermediate nursing care facilities. Standard mortgage loans were available from financial institutions for the construction of these facilities for both proprietary and non-profit organizations. The current Federal administration has imposed significant reductions in the Federal funds available to government agencies; interest rates now charged on most government loans or through guarantee programs have been increased from the previous 5% or less to rates representative of the current commercial financing. Financial institutions,

faced with a decline in available loan funds and increased costs for obtaining them, have retracted their participation in the financing of these facilities. Financial institutions recognize the ability of health care providers to repay the loan proceeds is contingent on Federal and State legislative appropriations and related volatile agency controlled Principles of Reimbursement. They consider the stability of this type of environment to be questionable, and therefore, not a viable investment for limited funds.

## PAYMENT FOR SERVICES RENDERED TO BENEFICIARIES OF GOVERNMENT PROGRAMS

### Cost Reimbursement Facilities

Payments by the government for care rendered to beneficiaries of the Medicaid and State Boarding Care program residing in intermediate care facilities and boarding homes participating in cost reimbursement programs are limited to specific "allowable costs." Representative government agencies, the purchaser of the service, unilaterally prescribe the specific costs considered allowable. There is no provision in the current Principles of Reimbursement associated with these programs to allow the efficient provider to receive a profit for his effort. A profit, (amount in excess of the total cost of rendering the service) can only be generated from charges to self-pay residents. The costs that are prescribed as "allowable" for each program do not include all costs that are necessary to operate a facility. Restrictive features of these Principles tend to be inflexible and unresponsive to the changing economic demands. These factors discourage the proprietary provider from expanding services to program beneficiaries, and seriously threaten the financial stability of non-profit organizations which serve primarily beneficiaries of these programs and very few self-pay residents.

Specific provisions of the current Principles of Reimbursement which are most detrimental to the expansion of current facilities and threaten the financial stability of ICF/MRs and boarding homes include:

- Salaries and fringe benefits paid to or for owners and administrators are not an allowable cost. An "Administrative and Policy Planning Allowance" (allowance) based on the licensed bed capacity of a facility is used in lieu of actual compensation and fringe benefit costs. The allowance was established at the implementation date of each set of Principles. It has not been increased since then. Appendix G is a reproduction of a position paper presented at a public hearing March 25, 1981, which summarizes the inequities inherent in the allowance for ICFs. The general concepts apply equally to the allowance provided for ICF/MRs and boarding homes.

- Interest expense incurred for working capital loans with a term of more than 15 months, and interest expense incurred on the late payment of vendor bills are not allowable costs. These restrictions were imposed by the Department in 1981 as changes to existing Principles. The Department also implemented a change which provided that all accrued expenses must be paid by a provider within six months of its fiscal year end; otherwise they are considered non-allowable expenses. These provisions ignore the economic reality and permanent working capital needs which exist. Any business which receives payment for services rendered subsequent to incurring the expenses for rendering these services requires working capital (cash) to pay the expenses incurred. These needs must be funded either from an accumulation of cash reserves from prior years profitable operations, or from working capital loans. Appendix H is a reproduction of a position paper presented at a public hearing May 6, 1981, which summarizes the inequities of these provisions.

Providers whose residents are all Medicaid or State Boarding program beneficiaries face a financial delimma. Government payments for the services rendered are based only on allowable cost. They contain no "profit", and they do not include total costs of operations. Payments are made subsequent to the time the costs associated with rendering care are incurred; therefore, a permanent need for working capital to cover non-allowable

expenses and allowable expenses incurred prior to the receipt of payment for services exists. This working capital can not be accumulated from profitable operations, because total costs always equal or exceed the resources received for the care rendered. The other normal alternative is a working capital loan; however, financial institutions will not make such loans or extend credit to businesses who can not repay the principal and interest of the loan. Facilities serving all government program beneficiaries can not repay the principal since they do not receive any funds for the care they render in excess of their current costs. Now these facilities will also not be able to pay the interest incurred on the loan beyond a term of fifteen months because it is a non-allowable cost.

Most ICF/MRs and boarding homes for the mentally retarded face these circumstances. They can not sustain their operations under these circumstances and there is a danger that currently available resources of this type will decrease, not increase, as a result of the financial crisis created by these provisions of the Principles.

- Long term debt service (mortgage payments) is covered by government payments for care through the payment of interest expense related to approved long term financing and depreciation expense (the amortization of a building's cost over its useful life). Actual principal payments on loans are not a reimbursable cost. Depreciation expense paid by government programs exceeds principal payments to the creditor during the first half of the term of the loan. Generally, these "extra" funds are used for working capital needs because of the problems discussed previously. During the latter half of the term of a mortgage loan, however, principal payments required to amortize the loan exceed annual depreciation expense. Those facilities forced to use initial years' depreciation reimbursement for working capital needs could eventually default on mortgage loan obligations. Financial institutions are aware of this situation, and will not provide financing for construction or renovation of facilities who are likely to face this crisis. Most ICF/MR facilities and boarding homes for the mentally retarded share this problem.

- Retirement plan contributions are not allowable costs. Since a provider is paid only allowable cost by the government programs, ICF/MRs and boarding homes can not afford to offer this benefit to employees. This places ICF/MRs and boarding homes at a competitive disadvantage for qualified health care personnel. The cost of such plans are a reimbursable cost for hospitals (Medicare regulations) and tax deductible for other industry employers, and therefore, are a common fringe benefit. Federal and State employees benefit from a retirement plan funded with government funds, but such a cost is not recognized as "allowable" for the Medicaid and Boarding Care programs. It is possible the quality of care that can be offered will decline if capable people are lured to other employers or industries as a result of this inconsistency.

- For proprietary providers a 10% return on equity is an allowable cost. No return on equity is permitted to non-profit providers. Most ICF/MRs and many boarding care facilities for the mentally retarded are non-profit organizations. During 1981 an investor could invest his funds in Money Market Certificates with six month maturities and yielding a return of 15% per year with substantially no risk of loss of his principal. A 10% return on equity, or no return on equity at all, certainly will not attract private capital for the expansion of residential facilities for the mentally retarded.

- The boarding home principles authorize the Commissioner of the Department to establish a ceiling on the reimbursement of allowable routine service costs. This eliminates reimbursement to providers even for some "allowable costs" incurred. Currently, this ceiling is $515 per month per resident. It was lower than this prior to July 1, 1981. Of the 62 cost reports for boarding home facilities licensed primarily for the care of the mentally retarded reviewed for this report, 35 exceeded the ceiling in existance for the fiscal year for which the reports were filed.

Provisions for a facility to obtain a "special circumstances allowance" generally is limited to additional minimum wage staff salaries and payroll taxes, and only if justified by the specific needs of the residents. Approval of such an allowance can provide some relief from the ceiling, but it does not insure that all allowable costs incurred will be reimbursed.

- o The cost of therapeutic and medical professionals is reimbursable only for that portion of the professional's time spent rendering direct care to a specific patient in accordance with the patients defined program needs. The cost for general consultation of a psychologist, therapists, and other medical professionals is not reimbursable, although it may be an essential cost to incur to provide overall professional guidance necessary to achieve the goals of communitization and habilitation in an ICF/MR or boarding care facility.

Fixed Rate Payments

Boarding homes currently paid a fixed monthly rate receive $335 per month per resident. This has remained the same for several years. Residents of independent living projects, supervised living and those residing with their families receive varying amounts of funding described in Appendix A-1. The payment to providers or residents utilizing each of these residential alternatives is not based on actual cost. There was no central source of financial data for these facilities.

There is a tendency for "flat rate payments" to remain unchanged regardless of increases in the quality of services rendered or inflation. Pertinent information should be assembled and evaluated to determine if the current payments are adequate to attract the number of providers necessary to accomodate the current and future needs of the mentally retarded.

## Day Care and Habilitation Programs

There is no central source of current financial information concerning the cost of operating day care and habilitation programs. Funding for these programs is from a variety of sources (Appendix A-1), generally through BMR grants, Title XX, or Vocational Rehabilitation funds. Some funding sources require that funds generated from the community or private support be used to reduce total budgeted costs of the organization; only the net cost is funded by government programs. The incentive for the provider to generate private funding is absent if each dollar received is deducted from another funding source. Without an adequate supply of day care and habilitation providers, the communitization and habilitation objectives can not be attained. Pertinent financial information is needed to evaluate the cost of these programs, and methods of payment for these services should be designed to attract the desired number of providers.

## Reimbursement Objectives

Solutions to the specific problems associated with current methods and amounts of government payments to providers for the care of program beneficiaries are complex, and are the foundation of a separate study. However, if private investment is to be attracted for the expansion of required residential settings, and if qualified providers are to be retained in this spectrum of health care, the concepts that govern the payment for the care rendered to program beneficiaries must be adjusted to reflect economic reality and to be competitive with alternative capital uses and employment opportunities.

## MORATORIUM ON ADDITIONAL BOARDING CARE FACILITIES

During the past few years, the State's appropriations for the payment for care of State Boarding Care beneficiaries has not met the necessary expenditures for their care. A deficit has been created. As a result, the Department

has imposed a moratorium on the addition of boarding care beds participating in this program. Only boarding care beds used for self-pay residents are being licensed. Boarding placements for State program beneficiaries can not be increased under these conditions. Alternative types of residences must be developed which do not sap the available State appropriations, or additional funding for this type of residence must be provided.

# PART II

## SECTION III

## COMPARATIVE COSTS OF RESIDENTIAL FACILITIES

The estimated cost associated with alternative forms of residential and program environments has been assembled in Appendix A. For analysis purposes, the actual residential settings utilized by 2,531 BMR clients as of April 1, 1981, was used as a representative population of beneficiaries of Federal and State funding sources. Appendix B reflects the total cost of care utilized by this population in their settings. Appendix C reflects the projected total cost of care for the model population if they could be placed in the most desirable residential and program setting available in April, 1981 based on estimated needs of each individual client. Appendix D reflects the projected total cost of care for the model population if they could be placed in the most desirable residential and program setting based on each individual's estimated needs, and if personal care homes had been available in April, 1981. Appendix E projects the potential State cost savings per resident that could be realized if personal care homes were available as alternatives for some residents of ICF/MRs, boarding homes and foster homes.

## FINANCIAL CONCLUSIONS

Certain general conclusions can be formulated from the comparative costs presented in the Appendices:

- The average estimated annual cost per resident is highest for the more institutionalized facilities and lowest for the less institutionalized settings. The highest estimated annual costs are incurred at Pineland ($36,883 per resident), residential treatment facilities ($33,757 per resident) and ICF/MRs ($28,440 per resident). The lowest annual costs are incurred in family living ($6,375 per resident), and independent living and food and lodging facilities ($7,467 per resident).

- State appropriations fund the highest proportion of the costs which are not covered by the Medicaid program. The cost for those placed in private residential treatment programs, (estimated annual cost of $640,000) the negotiated supplemental payments to providers of foster care (estimated annual cost of $112,000), and special circumstances allowances paid to selected boarding homes (estimated annual cost of $170,000) are borne 100% by the State.

- There are significant potential State cost savings through the development and utilization of personal care homes as an alternative residential facility for those individuals whose needs can be met in this environment. Total projected cost savings through the use of personal care homes for the model population are approximately $1,245,000 compared to the cost of care for the alternative residential placement using only existing types of facilities.

## ASSUMPTIONS RELATED TO COST ANALYSIS

A detail description of the methods and assumptions used to estimate the average annual cost of care per resident for each of the residential and program alternatives is provided in Appendix A-1. In addition, there are certain assumptions which pervade the entire cost analysis:

- Census of Mentally Retarded Citizens - There are many mentally retarded citizens in Maine that are not clients of BMR. The numbers of clients served by BMR are constantly changing as are the placement of these clients in alternative residential facilities to achieve the atmosphere most desirable for their needs and to achieve deinstitutionalization.

This analysis focuses on the effect on government cost of care and State funding caused solely by the placement of individuals in alternative residential and program facilities compared to those currently used. A fixed census of mentally retarded citizens has therefore been used for purposes of the cost analysis. BMR assembled statistical data concerning the residential and program facilities utilized by each of its clients in April, 1981. From information submitted by case workers, representatives of BMR also estimated the number of individuals in their client population whose needs could more appropriately be met in a different type of residential facility if placements were available.

Although representing only one segment of the mentally retarded citizens of Maine, the BMR statistical data was the best information available to establish a model to use for estimating the current cost of care, and projecting the changes in the cost of care caused by alternative placements.

- Cost Data - The sources used to establish estimated average annual costs consisted primarily of financial information for 1980 and the first six months of 1981. The costs are not current costs. Accordingly, the costs are relevant only for relative comparison purposes for alternative residential and program facilities, and for the determination of the relative changes in total governmental cost that may be realized by alternative placement of program beneficiaries.

- Components of Cost - The components of the estimated annual average cost of care per resident for each residential and program facility are limited to those costs recognized and funded by a Federal or State source for program beneficiaries. The focus is on the cost to the taxpayers for alternative residential facilities; the cost estimates do not include costs incurred by a private provider which are not allowable for purposes of determining the payments from a Federal or State program.

The estimated costs used in these analyses also do not represent the charge for care that may be made by a provider to self-pay residents. This charge may be higher than the estimated cost used in these analyses since it would include an amount sufficient to cover all costs incurred, plus a profit.

- Cost of Day Care and Habilitation Programs - There is no central source of financial information concerning the actual cost of operating a qualified day care and habilitation program outside the residential facilities. The cost of such programs at Pineland and for ICF/MRs is included in the estimated annual cost per resident for these facilities. Accordingly, to obtain comparable cost data for other types of facilities whose residents utilize outside programs, it was necessary to include an estimate of the cost of such programs.

  The ICF/MR Principles contain a maximum reimbursable allowance per resident per year of $4,575 for outside day care and habilitation programs. These Principles were developed by the Department with consultation from representatives of BMR. Although the $4,575 allowance was not derived from an analysis of financial data for current programs, it is the most current objective cost available, and it has been used as part of the total cost of each applicable residential setting whose residents utilize these programs.

- Cost of Support Staff and Case Workers - Substantially all clients of BMR benefit from the work of administrative personnel and case workers. The compensation paid these employees, together with other overhead costs, are funded by State appropriations. These costs have not been factored into the estimates of the costs per resident used for the financial analysis. It has been assumed these costs benefit each client proportionately, and would not be effected merely by a change in residential alternatives.

- Pineland Costs - Although the cost analysis in Appendices C and D project a decrease in Pineland residents, no decrease in total costs for the operation of Pineland has been projected. As deinstitutionalization is accomplished it is possible the Pineland facility will become more specialized and serve multiply and severely handicapped individuals on a short term or outpatient basis. It is also possible residential vacancies will be filled by new individuals entering the system whose needs will require specialized institutionalized care. It could be misleading to project geometric savings for each resident placed in an alternative residential setting. Accordingly, the analyses do not include any projected savings in the total cost or State funding associated with the Pineland operation. Savings would be increased above those projected to the extent of any actual cost reduction realized at Pineland as a result of alternative residential placement.

Appendix A

Appendix A is a summary of the average cost and funding sources for residential and program services. A summary follows:

| | Total Annual Cost Per Resident | Federal Percentage | State Percentage |
|---|---|---|---|
| Pineland Center | $36,883 | 47% | 53% |
| Residential Treatment Facilities | 33,757 | 24% | 76% |
| ICF/MR Facilities | 28,440 | 70% | 30% |
| Intermediate Nursing Care Facilities | 12,545 | 70% | 30% |
| Personal Care Homes | 11,275 | 77% | 23% |
| Boarding Homes - Cost Reimbursement Facilities | 10,827 | 38% | 62% |
| Supervised Living | 9,967 | 42% | 58% |
| Boarding Homes - Flat Rate Reimbursement Facilities | 8,595 | 48% | 52% |
| Foster Homes | 8,430 | 49% | 51% |
| Independent Living | 7,467 | 56% | 44% |
| Food & Lodging | 7,467 | 56% | 44% |
| Family | 6,375 | 56% | 44% |

Appendix B

This reflects the total estimated cost and funding sources for the care of BMR clients based on their current residential and program facilities.

The total annual cost of care for BMR clients based on present placement is approximately $38,100,000 with the Federal government contributing $19,400,000 and the State contributing $18,700,000.

Appendix C

This reflects the projected annual cost and funding sources for the care of BMR clients if each were placed in the most desirable residential setting based on each individual's program needs and the types of facilities available in April 1981.

The total projected cost is $41,100,000 with $21,800,000 funded from Federal sources and $19,300,000 by State sources. This represents an increase in annual Federal funding of $2,400,000 and an increase in State funding of $600,000 compared to the current placement of BMR clients depicted in Appendix B. No change in total Pineland operating costs have been projected, even though the census declines.

Appendix D

This reflects the projected annual cost and funding sources if BMR clients were placed in the most desirable residential and program setting based on their individual needs, with the availability of personal care homes. No change in Pineland's costs have been projected even though the census declines. It is assumed personal care homes would accomodate 371 BMR clients who would otherwise reside in an alternative residence, primarily ICF/MRs, boarding homes, or foster homes.

The total projected annual cost is $40,700,000 with $22,700,000 funded from Federal sources and $18,000,000 funded from State sources. This represents an increase in annual Federal funding of $3,300,000 and a decrease in State funding of $700,000 compared to current placement of BMR clients depicted in Appendix B.

Appendix E

This is an illustration of the projected monthly and annual cost savings per resident that could be realized by the use of the personal care homes for 371 current BMR clients. The projected State savings of $1,245,000 are based on the comparison of the estimated cost per resident of the personal care homes to the estimated cost for ICF/MRs, boarding homes, and foster homes.

This projection shows a monthly savings of $1,431 in total cost for each ICF/MR resident who could utilize the alternative personal care home. For each current resident of a boarding home or foster home who could utilize a personal care home there is an increase in the total projected monthly cost. However, both of these comparisons reflect savings of between $141 and $341 per resident per month in State appropriations. The shift to Title XIX funding for a substantial portion of the costs of personal care homes which are now funded by State appropriations for boarding home and/or foster home residents creates this effect.

The projected savings in Appendix E for boarding care and foster home residents are based only on the average cost of all residents using these types of facilities. The projected savings would be greater if it were assumed that all the special circumstance allowances paid to boarding homes (estimated at $170,000 per year) and all supplemental payments for foster care (estimated at $112,000 per year) could be eliminated. These are 100% State funded. This would occur if those utilizing a personal care home were the individuals for whom these special payments are now made.

PART II

SECTION IV

# PERSONAL CARE HOMES

# AN ALTERNATIVE RESIDENTIAL FACILITY

The current financial obstacles impeding the development of additional placements to accomodate deinstitutionalization objectives have stimulated interest in the development of the personal care home as an alternative type of residential facility which could enhance communitization and habilitation opportunities for some mentally retarded citizens. It could also reduce State appropriations required for the payment of the care of these individuals.

Current Federal Medicaid regulations allow the use of Medicaid Title XIX funds to pay for personal care services. In addition, new regulations implemented October 1, 1981, allow states to obtain a waiver from HCFA to have costs of therapeutic care and habilitation programming also covered by the Medicaid program. States may offer these services only to selected Medicaid program beneficiaries. If a waiver were obtained from HCFA, these facilities would rely upon the current Federal Supplemental Security Income to fund the cost of the room and board component of the care, and Title XIX funds would be utilized for the costs related to the therapeutic and habilitation programs. This could transfer a larger portion of the total cost of resident care to Federal sources from State appropriations. In addition to this advantage the following financial obstacles to the expansion of current facilities (Section II) may be avoided:

- Existing physical structures would be utilized for residences thereby avoiding high capital costs for construction and renovation of new ICF/MRs, intermediate nursing care facilities, and boarding homes.

- Some existing boarding homes and foster homes could be reclassified as personal care homes which would provide an immediate transfer of some current funding from State appropriations to the Title XIX program.

- Since the total compensation per resident projected for providers of personal care homes would be higher than that currently paid to a foster home or boarding home provider, it could be easier to attract additional qualified providers which would contribute to the expansion of less institutionalized facilities to accomplish the immediate objectives of the Decree.

In order to obtain a waiver, the State must assure HCFA of the following:

- Services will be provided under a written plan of care.
- Health and safety of the clients are protected.
- Community based services do not cost more, on an average per capita basis, than services provided to individuals in other Medicaid funded facilities, such as ICF/MRs.
- Adequate records will be maintained to provide financial accountability for funds expended.

All of these conditions can be met based on the information currently available.

Based on the projected potential cost savings in the State appropriations, it is feasible to establish this type of facility. It will not be appropriate for a majority of individuals served by BMR, but it may more appropriately address the program needs for some individuals and be a cost effective option in those situations.

# APPENDICES

APPENDIX A

ESTIMATED COST AND FUNDING SOURCES PER RESIDENT

FOR RESIDENTIAL AND PROGRAM SERVICES

| Type of Facility | Total Monthly Cost Per Resident | Federal Funding | | | |
|---|---|---|---|---|---|
| | | Title XIX | S.S.I. | Other | Total |
| Pineland | | | | | |
| Medicaid allowable costs | $1,687 | $1,181 | $ | $ | $1,181 |
| Estimated day care program costs in addition to Medicaid costs | 381 | 267 | | | 267 |
| Other costs borne by State | 1,006 | | | | |
| | 3,074 | 1,448 | | | 1,448 |
| ICF/MR Facilities | 2,370 | 1,659 | | | 1,659 |
| Boarding Home - cost reimbursement facilities | | | | | |
| Residential cost | 521 | | 225 | | 225 |
| Day Care & habilitation | 381 | | | 122 | 122 |
| | 902 | | 225 | 122 | 347 |
| Boarding Home - flat rate reimbursement facilities | | | | | |
| Residential cost | 335 | | 225 | | 225 |
| Day Care & habilitation | 381 | | | 122 | 122 |
| | 716 | | 225 | 122 | 347 |
| Foster Homes | | | | | |
| Residential cost | 272 | | 225 | | 225 |
| Special circumstances | 49 | | | | |
| Day Care & habilitation | 381 | | | 122 | 122 |
| | 702 | | 225 | 122 | 347 |
| Supervised Living | | | | | |
| Residential cost | 241 | | 225 | | 225 |
| Day Care & habilitation | 381 | | | 122 | 122 |
| Supervising staff | 208 | | | | |
| | 830 | | 225 | 122 | 347 |

APPENDIX A

| Title XIX Matching Funds | State Funding: Day Care Programs | Special Contracts | Boarding Care | Other State Expenditures | Total | Total Annual Cost |
|---|---|---|---|---|---|---|
| $506 | | | | | $506 | $20,244 |
| 114 | | | | | 114 | 4,575 |
| | | | | 1,006 | 1,006 | 12,064 |
| 620 | | | | 1,006 | 1,626 | 36,883 |
| 711 | | | | | 711 | 28,440 |
| | | | 296 | | 296 | 6,252 |
| | 259 | | | | 259 | 4,575 |
| | 259 | | 296 | | 555 | 10,827 |
| | | | 110 | | 110 | 4,020 |
| | 259 | | | | 259 | 4,575 |
| | 259 | | 110 | | 369 | 8,595 |
| | | | | 47 | 47 | 3,264 |
| | | 49 | | | 49 | 591 |
| | 259 | | | | 259 | 4,575 |
| | 259 | 49 | | 47 | 355 | 8,430 |
| | | | | 16 | 16 | 2,892 |
| | 259 | | | | 259 | 4,575 |
| | | | | 208 | 208 | 2,500 |
| | 259 | | | 224 | 483 | 9,967 |

ESTIMATED COST AND FUNDING SOURCES PER RESIDENT FOR RESIDENTIAL AND PROGRAM SERVICES

APPENDIX A
(Concluded)

| Type of Facility | Total Monthly Cost Per Resident | Federal Funding | | | |
|---|---|---|---|---|---|
| | | Title XIX | S.S.I. | Other | Total |
| Independent Living | | | | | |
| Residential cost | 241 | | 225 | | 225 |
| Day Care & habilitation | 381 | | | 122 | 122 |
| | 622 | | 225 | 122 | 347 |
| Family | | | | | |
| Resident cost | 150 | | 150 | | 150 |
| Day Care & habilitation | 381 | | | 122 | 122 |
| | 531 | | 150 | 122 | 272 |
| Food & Lodging | | | | | |
| Residential cost | 241 | | 225 | | 225 |
| Day Care & habilitation | 381 | | | 122 | 122 |
| | 622 | | 225 | 122 | 347 |
| Residential Treatment Facilities | 2,813 | | | 676 | 676 |
| Intermediate Care Nursing Homes | 1,045 | 732 | | | 732 |
| Personal Care Homes | | | | | |
| Residential cost | 558 | 233 | 225 | | 458 |
| Day Care & habilitation | 381 | 267 | | | 267 |
| | 939 | 500 | 225 | | 725 |

APPENDIX A
(Concluded)

| State Funding | | | | | | |
|---|---|---|---|---|---|---|
| Title XIX Matching Funds | Day Care Programs | Special Contracts | Boarding Care | Other State Expenditures | Total | Total Annual Cost |
| | | | | 16 | 16 | 2,892 |
| | 259 | | | | 259 | 4,575 |
| | 259 | | | 16 | 275 | 7,467 |
| | | | | | | 1,[illegible] |
| | 259 | | | | 259 | 4,[illegible] |
| | 259 | | | | 259 | 6,375 |
| | | | | 16 | 16 | 2,892 |
| | 259 | | | | 259 | 4,575 |
| | 259 | | | 16 | 275 | 7,467 |
| | | 889 | | 1,248 | 2,137 | 33,757 |
| 313 | | | | | 313 | 12,545 |
| 100 | | | | | 100 | 6,[illegible]0 |
| 114 | | | | | 114 | 4,575 |
| 214 | | | | | 214 | 11,[illegible]5 |

Appendix A-1

## BASIS FOR ESTIMATED COST AND FUNDING SOURCES

The estimated average monthly cost of care per resident for each residential facility summarized in Appendix A, and the determination of the amount of cost funded by each government source necessitated the use of certain assumptions. The information for estimates was provided primarily by representatives of BMR or the Department unless stated otherwise below.

### Pineland Center

The Medicaid cost report submitted to the Maine Department of Human Services for the fiscal year ended June 30, 1980, was utilized as the basic source of financial information. This report reflected total direct operating costs of $11,112,000. The total allowable cost determined by the Department of Human Services Audit Division for the Medicaid program was $6,097,000, or $1,687 per month per resident based on the total resident days. The costs related to day care and habilitation programs incurred by Pineland were not allowable as a reimbursable cost for the Medicaid program for that year. It was not practical to determine the specific costs associated with day care and habilitation programs which are now allowable for the Medicaid program. Accordingly, we assumed the total cost of the day care and habilitation program per resident was $4,575 per year, or $381 per month (Section III). The total allowable costs of Medicaid program and the day care and habilitation programs were deducted from the total direct costs of Pineland to estimate the additional costs of $3,636,000, or $1,006 per resident per month.

The allocation of the cost of day care and habilitation programs between Federal and State appropriations is 32% Federal and 68% State. This information was derived by a composite summary of the approximate allocation of funds used for these programs by Voc. Rehab., BMR, and Title XX in the State. This information was provided by representatives of BMR. Costs that are allowable for the Medicaid program are funded approximately 70% from Federal sources and 30% from State matching funds. Other costs incurred by Pineland are funded 100% from State appropriations.

Appendix A-1
Continued

ICF/MR Facilities

Most of these facilities were licensed on or subsequent to January 1, 1981. As a result, there was little actual financial information available. At the time we assembled information for this report, there were 22 ICF/MR facilities licensed. We reviewed cost reports submitted to the Audit Division of the Department of Human Services for each of these facilities. The average cost per patient day ranged from $35.40 to $109.44. The comparison of the cost data was distorted because some of these reports included periods during which the facilities were actually boarding homes, not ICF/MRs, and most of the other reports contained projected expense information instead of actual information.

We excluded from the data those homes whose cost reports presented financial information prior to 1981 since these were primarily reports for facilities operating as boarding homes, not ICF/MRs. Of those 14 homes remaining who submitted primarily projected 1981 information, the average cost per patient day was $77.93, which we anticipate will be less than the actual 1981 costs will reflect when they are available based on our knowledge of actual ICF/MR operations. However, since this was the only documented information available, the average daily costs of $77.93 were utilized, resulting in monthly costs per resident of $2,370. This includes the cost of day care and habilitation programs.

ICF/MR facilities were all licensed for participation in the Medicaid program. We have assumed that the entire estimated monthly cost per resident of $2,370 would be allowable under this program. Accordingly, these costs are funded approximately 70% from Federal sources and 30% from State matching funds.

Boarding Homes - Cost Reimbursement Facilities

We reviewed cost reports submitted by 62 boarding home facilities licensed primarily for care of the mentally retarded which were submitted for the most recently completed fiscal year of each facility to the Audit Division of the Deparment of Human Services. Some of these reports had not been audited by

the Department at the time of our review. Most of the financial information was for periods including at least six months of 1980. The average cost per resident day ranged from $11.70 to $31.73. We utilized the total number of resident days shown on these reports and the total allowable costs to determine an average allowable cost per resident day of $17.12, or $521 per month. In addition, most residents of these boarding care facilities utilize day care and habilitation programs. The estimated average monthly cost per resident for these programs is $381 as discussed previously.

The funding of the residential cost of $521 per month is provided by Federal Supplemental Security Income of $225 and State appropriations of $296. The day care and habilitation program cost is funded 32% from Federal funds and 68% from State funds.

Boarding Homes - Flat Rate Payment Facilities

These facilities receive a fixed payment for residential care of $335 per month per resident. This is composed of $225 of Federal Supplemental Security Income and $110 of State appropriations. In addition, most of the residents of these facilities utilize outside day care and habilitation programs. The $381 per month per resident of estimated cost for these programs and the funding thereof is as discussed previously.

Foster Homes

Providers are paid a fixed amount of $272 per month per resident for the residential care. $225 of this is provided by Federal Supplemental Security Income and the remaining $47 is provided by State appropriations. In addition, $112,000 of State appropriations are currently utilized to provide supplemental payments for 38 BMR clients who have special needs that are provided by the foster homes in which they reside. For purposes of determining an average estimated cost per resident, this extra funding has been allocated to all foster home residents resulting in an average monthly cost per resident of $49, funded 100% from State appropriations. Most foster home residents utilize outside day care and habilitation programs and the estimated cost of $381 per month is funded as previously discussed.

Appendix A-1
Continued

Supervised Living

The residential cost for individuals using supervised living accomodations is $241 a month with $225 provided from Supplemental Security Income and $16 from State supplemental appropriations. Since the professional staff required to provide 24 hour supervision and training for these individuals is an essential component of the cost, and is comparable to the staffing costs incurred in a more institutionalized setting, we included an estimated cost of $208 per month per resident in the total cost of care rendered for this type of facility. This amount was estimated based on average annual total compensation of $15,000 per supervisory person capable of supervising 6 individuals in a supervised living arrangement. In addition, most individuals residing in these accomodations utilize an outside day care and habilitation program for which the estimated monthly cost per resdient of $381 has been added and is funded as discussed previously.

Independent Living

The estimated cost associated with independent living and the method of funding of these components is the same as the Supervised Living discussed above, except there are no costs for supervisory personnel.

Family Living

There are generally no direct payments made to families for the care of mentally retarded family members. Many mentally retarded citizens receive Supplemental Security Income, but not all of them. We have assumed that an average of $150 per month per individual would be received from Supplemental Security Income. Most individuals residing in these accomodations utilize an outside day care and habilitation program and the $381 estimated cost per month has been included in the total estimated cost and is funded as discussed previously.

Food & Lodging Accomodations

The normal costs associated with these types of accomodations are the same as those associated with independent living and are provided from the same funding sources.

Residential Treatment Facilities

Based on information provided by representatives of BMR there are currently 60 BMR clients utilizing various types of residential treatment facilities. Some use privately operated facilities, others use Pineland, Levenson Center, Augusta Mental Health Institute and Bangor Mental Health Institute. Average annual costs range from $40,000 per resident in the privately operated facilities to $30,000 per resident for some of the State operated facilities. Based on the estimated number of individuals served by each type of facility and the average cost associated with each resident, we estimated the combined average cost per month per client to be $2,813. Some of the funding is from Federal sources and some from State sources with the apportionment varying with each type of facility. We calculated an estimated composite allocation of 24% Federal and 76% State funds.

Intermediate Nursing Care Facilities

Substantially all of these facilities are licensed for participation for Medicaid Title XIX and are required to file annual Medicaid cost reports with the Audit Division of the Department of Human Services. The Audit Division and the Maine Health Care Association, which is an organization of nursing homes in Maine, maintain continuing statistical data regarding the average cost per day per resident in these facilities. Based on information obtained from these sources and data in our client files for a representative sample of cost reports submitted for fiscal years ending in 1980, we used an average cost per day for care in these facilities of $34.37, or $1,045 per resident per month.

Appendix A-1
Concluded

Personal Care Homes

Since this type of facility is relatively new and in the development stages, there was no actual financial information available representing the cost of operations for these facilities. Information provided to us by BMR representatives was based primarily on their experience in attempting to locate qualified providers to render this type of care. It was estimated that providers could be attracted if the payment was approximately $6,700 per year, or $558 per resident per month. Expected funding of this care would consist of $225 of Federal Supplemental Security Income for residential cost, and the remaining $333 per month from the Medicaid Title XIX program, 70% from Federal funds and 30% from State Title XIX matching funds. This assumes the applicable waiver from HCFA will be obtained to permit Medicaid funding. In addition, it is assumed residents of these facilities will utilize outside day care and habilitation programs. The $381 estimated cost per month per resident has been included in the overall estimated cost of this type of facility and will be funded as discussed previously.

ANNUAL COSTS AND FUNDING SOURCES
FOR CURRENT PLACEMENT OF BMR CLIENTS IN
RESIDENTIAL AND PROGRAM SERVICES

APPENDIX B

| Type of Residence | Current Residents Served | Annual Cost per Resident: Total (Appendix A) | Annual Cost per Resident: Source of Funding: Federal | Annual Cost per Resident: Source of Funding: State | Total Annual Cost: Total | Total Annual Cost: Source of Funding: Federal | Total Annual Cost: Source of Funding: State |
|---|---|---|---|---|---|---|---|
| Pineland Center | 350 | $ 36,883 | $ 17,374 | $ 19,509 | $12,909,050 | $ 6,080,900 | $ 6,828,150 |
| ICF/MR Facilities | 264 | 28,440 | 19,908 | 8,532 | 7,508,160 | 5,255,712 | 2,252,448 |
| Boarding Homes - Cost Reimbursement Facilities | 450 | 10,827 | 4,165 | 6,662 | 4,872,150 | 1,874,250 | 2,997,900 |
| Boarding Homes - Flat Rate Reimbursement Facilities | 167 | 8,595 | 4,165 | 4,430 | 1,435,365 | 695,555 | 739,810 |
| Foster Homes | 190 | 8,430 | 4,165 | 4,265 | 1,601,700 | 791,350 | 810,350 |
| Supervised Living | 44 | 9,967 | 4,165 | 5,802 | 438,548 | 183,260 | 255,288 |
| Independent Living | 83 | 7,467 | 4,165 | 3,302 | 619,761 | 345,695 | 274,066 |
| Family | 788 | 6,375 | 3,265 | 3,110 | 5,023,500 | 2,572,820 | 2,450,680 |
| Food & Lodging | 12 | 7,467 | 4,165 | 3,302 | 89,604 | 49,980 | 39,624 |
| Residential Treatment Facilities | 60 | 33,757 | 7,957 | 25,800 | 2,025,420 | 477,420 | 1,548,000 |
| Intermediate Care Nursing | 123 | 12,545 | 8,787 | 3,758 | 1,543,035 | 1,080,801 | 462,234 |
| Total | 2,531 | | | | $38,066,293 | $19,407,743 | $18,658,550 |

APPENDIX C

# PROJECTED ANNUAL COSTS AND FUNDING SOURCES FOR ALTERNATIVE PLACEMENT OF BMR CLIENTS IN EXISTING RESIDENTIAL AND PROGRAM SERVICES

| | Population Classification | | |
|---|---|---|---|
| | Current (Appendix B) | Net Relocation | Proposed Classification |
| Pineland | 350 | (63) | 287 |
| ICF/MR Facilities | 264 | 148 | 412 |
| Boarding Home Cost Reimbursement Facilities | 450 | 95 | 545 |
| Boarding Home - Flat Rate Facilities | 167 | 35 | 202 |
| Foster Homes | 190 | 75 | 265 |
| Supervised Living | 44 | 140 | 184 |
| Independent Living | 83 | (22) | 61 |
| Family | 788 | (285) | 503 |
| Food & Lodging | 12 | ( 8) | 4 |
| Residential Treatment Facilities | 60 | (52) | 8 |
| Intermediate Nursing Care Facilities | 123 | (63) | 60 |
| | 2,531 | -0- | 2,531 |

| Annual Cost Per Resident (Appendix B) | | | Total Annual Cost | | |
|---|---|---|---|---|---|
| Total | Federal | State | Total | Federal | State |
| $ | $ | $ | $12,909,050 | $ 6,080,900 | $ 6,828,150 |
| 28,440 | 19,908 | 8,532 | 11,717,280 | 8,202,096 | 3,515,184 |
| 10,827 | 4,165 | 6,662 | 5,900,715 | 2,269,925 | 3,630,790 |
| 8,595 | 4,165 | 4,430 | 1,736,190 | 841,330 | 894,860 |
| 8,430 | 4,165 | 4,265 | 2,233,950 | 1,103,725 | 1,130,225 |
| 9,967 | 4,165 | 5,802 | 1,833,928 | 766,360 | 1,067,568 |
| 7,467 | 4,165 | 3,302 | 455,487 | 254,065 | 201,422 |
| 6,375 | 3,265 | 3,110 | 3,206,625 | 1,642,295 | 1,564,330 |
| 7,467 | 4,165 | 3,302 | 29,868 | 16,660 | 13,208 |
| 33,757 | 7,957 | 25,800 | 270,056 | 63,656 | 206,400 |
| 12,545 | 8,787 | 3,758 | 752,700 | 527,220 | 225,480 |
| | | | $41,045,849 | $21,768,232 | $19,277,617 |

APPENDIX D

# PROJECTED ANNUAL COSTS AND FUNDING SOURCES FOR ALTERNATIVE PLACEMENT OF BMR CLIENTS UTILIZING PERSONAL CARE HOMES

| | Population Classification | | |
|---|---|---|---|
| | Current (Appendix B) | Net Relocation | Proposed Classification |
| Pineland | 350 | (63) | 287 |
| ICF/MR Facilities | 264 | 98 | 362 |
| Boarding Homes - Cost Reimbursement Facilities | 450 | (69) | 381 |
| Boarding Homes - Flat Rate Reimbursement | 167 | (26) | 141 |
| Foster Homes | 190 | (21) | 169 |
| Supervised Living | 44 | 140 | 184 |
| Independent Living | 83 | (22) | 61 |
| Family | 788 | (285) | 503 |
| Food & Lodging | 12 | ( 8) | 4 |
| Residential Treatment Facilities | 60 | (52) | 8 |
| Intermediate Nursing Care Homes | 123 | (63) | 60 |
| Personal Care Homes | | 371 | 371 |
| Total | 2,531 | -0- | 2,531 |

| Annual Cost Per Resident (Appendix B) | | | Total Annual Cost | | |
|---|---|---|---|---|---|
| Total | Federal | State | Total | Federal | State |
| $ | $ | $ | $12,909,050 | $ 6,080,900 | $ 6,828,150 |
| 28,440 | 19,908 | 8,532 | 10,295,280 | 7,206,696 | 3,088,584 |
| 10,827 | 4,165 | 6,662 | 4,125,087 | 1,586,865 | 2,538,222 |
| 8,595 | 4,165 | 4,430 | 1,211,895 | 587,265 | 624,630 |
| 8 430 | 4 165 | 4 265 | 1,424,670 | 703,885 | 720,785 |
| 9,967 | 4,165 | 5,802 | 1,833,928 | 766,360 | 1,067,568 |
| 7,467 | 4,165 | 3,302 | 455,487 | 254,065 | 201,422 |
| 6,375 | 3,265 | 3,110 | 3,206,625 | 1,642,295 | 1,564,330 |
| 7,467 | 4,165 | 3,302 | 29,868 | 16,660 | 13,208 |
| 33,757 | 7,957 | 25,800 | 270,056 | 63,656 | 206,400 |
| 12,545 | 8,787 | 3,758 | 752,700 | 527,220 | 225,480 |
| 11,275 | 8,700 | 2,575 | 4,183,025 | 3,227,700 | 955,325 |
| | | | $40,697,671 | $22,663,567 | $18,034,104 |

APPENDIX E

COMPARATIVE ANNUAL COST SAVINGS

UTILIZING PERSONAL CARE HOMES

| | ICF/MR | | | Boarding Homes Cost Reimbursement | | | Boarding Homes Flat Rate | | | Foster Homes | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Total | Federal | State | Total | Federal | State | Total | Federal | State | Total | Federal | State |
| Monthly cost per resident (Appendix A) | $ 2,370 | $ 1,659 | $ 711 | $ 902 | $ 347 | $ 555 | $ 716 | $ 347 | $ 369 | $ 702 | $ 347 | $ 355 |
| Estimated monthly cost per resident for Personal Care Facilities | 939 | 725 | 214 | 939 | 725 | 214 | 939 | 725 | 214 | 939 | 725 | 214 |
| Monthly cost (savings) per resident for Personal Care Facilities compared to current available residential facilities | (1,431) | ( 934) | (497) | 37 | 378 | (341) | 223 | 378 | (155) | 237 | 378 | (141) |
| Estimated number of residents whose needs could best be served by Personal Care Facilities instead of current types of facilities shown in Appendix C, Total of 371 residents | 50 | | | 164 | | | 61 | | | 96 | | |
| Total projected monthly cost increase (savings) due solely to use of Personal Care Facilities instead of classification of residents using existing facilities | $ (71,550) | $ (46,700) | $(24,850) | $ 6,068 | $ 61,992 | $(55,924) | $ 13,601 | $ 23,058 | $ (9,455) | $ 22,752 | $ 36,288 | $( 13,536) |
| Total projected annual cost increase (savings) by type of facility | $ (858,600) | $(560,400) | $(298,200) | $ 72,816 | $ 743,904 | $(671,088) | $ 163,236 | $ 276,696 | $(113,460) | $ 273,024 | $ 435,456 | $(162,432) |
| Total projected annual cost increase (savings) by funding source | Federal | | | | | | $ 895,656 | | | | | |
| | State | | | | | | $(1,245,180) | | | | | |
| | Total | | | | | | $ (349,524) | | | | | |

APPENDIX F

# ILLUSTRATIONS OF CAPITAL COST FOR NEW CONSTRUCTION AND MAJOR RENOVATIONS

The following examples illustrate the impact of capital costs on the total cost of care.

## Intermediate Care Facilities - New Construction

| Assume the following facts: | ICF/MR | Intermediate Nursing Care Facility |
|---|---|---|
| Total number of beds constructed | 20 | 50 |
| Total average cost per bed | $40,000 | $25,000 |
| Total construction cost | $800,000 | $1,250,000 |
| Total invested capital -10% which is assumed to be the cost of land | $80,000 | $125,000 |
| Mortgage loan principal and cost of facility subject to depreciation | $720,000 | $1,125,000 |
| Annual interest rate for 20 year loan | 15% | 15% |
| Average useful life of the facility for depreciation purposes | 33 yrs. | 33 yrs. |

The resulting annual depreciation and interest costs and the effect on total annual cost of care per resident would be as follows:

APPENDIX F
(Continued)

| | ICF/MR | Intermediate Nursing Care Facility |
|---|---|---|
| Annual depreciation expense | $21,818 | $34,091 |
| Annual interest expense (1st year of loan) | $129,098 | $201,717 |
| Total depreciation and interest cost per year | $150,916 | $235,808 |
| Total annual resident days assuming 95% occupancy | 6,935 | 17,337 |
| Average depreciation and interest cost per day | $21.76 | $13.60 |
| Average depreciation and interest cost per month per resident | $661.86 | $413.67 |
| Average depreciation and interest cost per year per resident | $7,942 | $4,965 |

Boarding Home - Acquisition and Renovation of Existing Residence

Assume the initial acquisition cost of the building is $80,000, and renovations total $50,000 for a total acquisition cost of $130,000. Also assume the facility serves 12 residents, 90% of the total cost of acquisition and renovation is financed by a 15% 20 year loan, and the useful life of the building is 25 years. The annual depreciation and interest cost per resident is:

APPENDIX F
(Concluded)

| | |
|---|---|
| Total interest expense (1st year of loan) | $20,978 |
| Total depreciation expense assuming 90% of the total cost pertains to depreciable assets and 10% to the cost of land | 4,680 |
| Total annual capital cost | $25,658 |
| Resident days, assuming 95% occupancy | 4,161 |
| Average interest and depreciation cost per day per resident | $6.17 |
| Monthly interest and depreciation cost per month per resident | $187.67 |
| Average annual interest and depreciation cost per resident | $ 2,252 |

BERRY, DUNN & MCNEIL
CERTIFIED PUBLIC ACCOUNTANTS
96 HARLOW STREET
BANGOR, MAINE - 04401
TELEPHONE 207 942-6343

APPENDIX G

STATEMENT OF POSITION

Subject: Principles of Reimbursement for Long Term Care Facilities
Changes to Principle 4112.1
Increase in Administrative and Policy Planning Allowance

Submitted to: Commissioner Michael R. Petit
State of Maine Department of Human Services

Submitted for: Public Hearing of March 25, 1981

## INTRODUCTION

Our firm renders professional services in financial and cost reimbursement matters to several nursing home facilities in Maine. Members of our firm have been involved in the health care field since the implementation of Medicare in 1966, and we have served as consultants to the Maine Health Care Association (Association) on reimbursement matters since 1975. It is on behalf of our clients in the nursing home industry and our position as consultants for the Association that we support the changes to the Maine Medicaid Administration and Policy Planning Allowance (allowance) petitioned by the Association.

## CONSLUSIONS

The Association has petitioned the Department to change Principle 4112.1 of the Maine "Principles of Reimbursement for Long Term Care Facilities" (Principles) to provide:

- o A 20% increase in the current fixed Administrative and Policy Planning Allowance based on licensed beds to be effective January 1, 1982.

- o Increase the allowance annually thereafter by a percentage equal to the annual increase in the Consumer Price Index for the preceeding year.

These changes are necessary to compensate for inflation since January 1, 1978, the implementation date of the current allowance, and to provide an equitable means of adjusting the allowance for actual cost increases on an annual basis in the future. Furthermore, the requested changes are necessary to correct historical reimbursement inequities; they are reasonable judged on the basis of current economic facts; they are reasonable compared to an evaluation of compensation granted to employees of the Maine government; they are consistent with the fundamental tenets of the Medicaid Principles of Reimbursement; and they are essential to provide the capability for providers to retain qualified administrative personnel to assure that the current quality of patient care can be sustained.

## HISTORY

The initial Medicaid Principles of Reimbursement for Long Term Care Facilities developed by the Department were issued in September 1972. These Principles contained a provision for an allowance, based on licensed beds, to be added to allowable costs in lieu of all actual compensation and fringe benefits paid or attributed to the owner of the facility. Compensation of non-owner administrators was not included in this allowance; therefore, reasonable compensation and allowable fringe benefits paid to non-owner administrators were allowable costs ( Principal 10 (a) of 1972 Principles).

No increase in the original allowance was made until revised Medicaid Principles were implemented on January 1, 1978. The allowance contained in the 1978 Principles constituted a 33% increase from the original 1972 allowance. However, this apparent benefit was completely offset by the following factors:

- The Consumer Price Index increased 48.5% from 1972 to December 31, 1977 (125.3 in 1972 to 186.1 in December 1977).

- The allowance was expanded to be in lieu of not only owner's compensation and fringe benefits, but also to be in lieu of compensation and fringe benefits of Administrators and any other personnel involved with "administration and policy planning functions" as defined by Principles 4112.2 and 4112.3.

- Fringe benefits covered by the allowance were defined to include Social Security tax, Workmen's Compensation insurance, Federal and State Unemployment tax, contributions to retirement plans, and health, life and disability insurance premiums. Most of these costs are payroll taxes or liability insurance mandated by State and Federal laws. They are not fringe benefits which are discretionary on the part of the employer. Furthermore, the rates that the employer is required to pay increase annually with no control by the employer.

- The Department eliminated the Consumer Price Index inflation factor from the 1972 Principles which was applied to the net book value of real property for determination of the allowable return on a provider's equity. This resulted in a reduction of total allowable costs for some providers of as much as $30,000 per year.

- Failure to provide for annual increases in the 1978 allowance defied economic reality, and has completely erroded the reasonableness of the reimbursement for administrative personnel costs during the last three years even if the allowance was deemed reasonable in 1978.

## ILLUSTRATION

Appendix A is a conservative illustration of the inadequacy of the current allowance as reimbursement for actual costs incurred by providers. Actual costs in this illustration include only the costs for a licensed administrator. These costs are compared to the current administrative allowance to determine the costs which are not reimbursed to the provider for required administrative personnel.

For purposes of these calculations, we assumed that the current administrative allowance represented reasonable compensation and fringe benefits necessary to retain a qualified licensed administrator on January 1, 1978. We assumed that fringe benefits ranged between $4,000 and $5,000 at that time. We utilized sample facilities licensed for 40,50,75 and 100 beds. Respective salaries on January 1, 1978, were $15,000, $17,000, $20,000 and $23,000, $4,000 to $5,000 less than the allowance. We utilized the changes in the Consumer Price Index to inflate the January 1, 1978 salaries to a salary as of Decmeber 31, 1980 adjusted solely for inflation. This does not provide for any increase that might normally be granted for individual merits or capabilities such as length of service, increased competence, assumption of additional responsibility, or additional educational requirements imposed by regulatory authorities.

We calculated the normal fringe benefits which must be paid by the provider based on the imputed 1980 salaries. These include Social Security tax, Unemployment taxes, Workmen's Compensation Insurance, health, disability, major medical and group term life insurance premiums, and retirement

plan benefits. These amounts were calculated at the applicable 1980 statuatory rates, or were estimated based on information from selected clients of our firm. The total calculated fringe benefits and wages at December 31, 1980 were compared to the current administrative allowance to determine the amount of costs that providers are required to incur to obtain a qualified administrator required by State licensing regulations for which the Medicaid Principles do not provide reimbursement. This ranges from $6,200 for a 40 bed facility to $9,200 for a 100 bed facility.

Based on this illustration the administrative allowance is now 33% less than actual reasonable costs without even considering additional costs for owner's or other administrative personnel whose salaries and fringes are also disallowed in addition to those attributable to administrators. Since the implementation date of the increase is to be January 1, 1982, the severity of the problem is greater than the illustration which is based on December 31, 1980 costs. The petitioned changes are essential to correct these reimbursement inequities.

## Additional Criteria Supporting the Petitioned Changes

There are several criteria in addition to the current reimbursement inequity which support the propriety and reasonableness of the petitioned increases.

o Compensation of State of Maine Employees

Inflation is an economic reality. Although none of us enjoy the continuing escalation of the cost of living, all employers recognized they must provide increased compensation to qualified employees in order to retain them. Reference to the cost of living increases negotiated by the Maine State Employees Association with the State of Maine since 1979 illustrates the State's recognition of this need. Based on information provided to us by representatives of the Maine State Employees Association, the following increases have been implemented:

- o April 1, 1979, - an 8.1% increase, retroactive for one year.
- o July 1, 1979, - a 7.9% increase for the year ending June 30, 1980.
- o July 1, 1980, - a 7.3% increase for the year ending June 30, 1981.

Negotiations are now in process for additional increases, and it is logical to assume some increase will be granted if State Government intends to continue functioning. The actual increases granted to State employees for 1978 through 1980 constitute a 25% increase in base compensation for the period, exclusive of the various fringe benefits also provided. This compares to only a 20% increase petitioned by the Association which includes compensation and fringes and which will not be effective until 1982.

o Basis of Medicaid Reimbursement Principles

The Medicaid Principles of Reimbursement are developed from the basic tenet that the reasonable and necessary costs of rendering patient care are allowable for reimbursement purposes. This is specifically stated in Principle 1010 et al. Substantially all costs allowable for reimbursement under these Principles are defined in terms of their nature, not a fixed dollar amount. Accordingly, utility costs, supply costs, salary costs for non-administrative personnel, etc., are all reimbursed annually based on current costs incurred. The effect of inflation is automatically provided for these patient care costs. The allowance for administrative personnel should not be treated differently. It is a necessary cost of patient care which is evidenced by the State licensing requirement that every facility in excess of forty (40) beds must have a qualified licensed administrator. Therefore, the allowance for these costs should be treated like other allowable costs, and it must be indexed to annual inflation to be consistent.

o Medicare Regulations

The precedent for Medicaid Principles of Reimbursement were the Federal Medicare Principles of Reimbursement (HIM-15). From inception Medicare Principles specifically provided reimbursement

for the "reasonable compensation" of an owner of a facility (Reg. 405.426). Reasonable compensation includes base salary plus all fringes. In order to evaluate reasonableness, Medicare regulations provide for the assembly of compensation by geographic area and by similar facilities for functions performed by non-owners to compare to owners compensation for similar services. In addition, the qualifications of each individual owner for the functions he performs are considered, such as experience, educational requirements of the position, professional affiliation, size of facility, and results generated by the owner/employee. There are no limitations on the reimbursement for compensation paid to non-owner administrators. Although the Association is not requesting that the Maine Medicaid Principles adopt an actual compensation approach, it is important to note the more flexible reimbursement philosophy of the Federal Medicare regulations compared to the reimbursement strangulation inherent in the current Maine Medicaid allowance concept.

o Impact on Quality of Care

Approximately 80% of the patients in Maine nursing homes are Medicaid patients. Because of increased government funding necessitated by the increasing Medicaid patients, a stream of Federal and State regulations governing licensing, operations, and reimbursement have inundated the nursing homes during the

last ten years. While some of these regulations have enhanced the quality of patient care, all of them have increased the cost of that care. But it is the nursing home industry that is criticized by Federal and Maine agencies for the resulting increases in health care costs. They cite the increases in total Medicaid expenses over various periods to support their position. The government seeks to convince itself and the public that more regulation and less reimbursement should be directed toward the nursing home industry as the solution to the increased costs. They neglect to cite the increased costs that have been created by the government regulations, the increased quality of care provided to the patients, and the increased number of patients now being served that result in the total cost increase. It is more expedient to direct blame toward the providers for cost increases than to admit the regulatory contribution to increased costs made by the government agencies.

The current allowance is a prime example of the inconsistency between reimbursement principles and the regulations governing the operation of nursing homes implemented to assure quality patient care. A licensed administrator is required for all facilities with forty (40) beds or more. The education and experience requirements for a licensed administrator have been continuously increased by regulations since 1972 to improve the care rendered patients. Principle 1015 of the current Principles of Reimbursement states:

"Costs incurred to comply with changes in Federal or State laws and regulations for increased care and improved facilities are to be considered reasonable and necessary costs."

The reimbursement to the provider for the costs of complying with these regulations, however, has been effectively decreased since 1972. It is time to stop talking about regulations, quality care, and reimbursement of the cost of care as though they are independent subjects. They are interrelated, and regulations should be implemented only if they actually result in improved patient care, and only if the reimbursement mechanism is adjusted to insure the associated cost is to be reimbursed.

Reimbursement for the cost of administrative personnel must be commensurate with the cost providers must incur to obtain qualified people. The quality of care will deteriorate if this is not done. Quality patient care cannot be obtained through regulations alone; it requires the retention of qualified people, which requires appropriate funding.

## SUMMARY

We urge the adoption and funding of the petitioned changes in the Maine Medicaid Principles of Reimbursement to correct the current reimbursement

inequity for nursing home providers and to prevent the emminent errosion of the quality of administrators in Maine who are responsible for the overall supervision of the care for the patients.

Respectfully submitted,

BERRY, DUNN & MCNEIL

By: Michael T. McNeil

APPENDIX A

ADMINISTRATION AND POLICY PLANNING ALLOWANCE 13.II-60

SCHEDULE OF MEDICAID ALLOWANCE COMPARED TO REASONABLE COMPENSATION FOR QUALIFIED ADMINISTRATORS

| | Licensed Beds | | | |
|---|---|---|---|---|
| | 40 | 50 | 75 | 100 |
| Gross wages of Administrators as of January 1, 1978 | $15,000 | $17,000 | $20,000 | $23,000 |
| Inflation adjustment for increase in Consumer Price Index since January 1, 1978 | | | | |
| 1978 increase in C.P.I.-9.027% | 109.027 | 109.027 | 109.027 | 109.027 |
| | $16,354 | $18,535 | $21,805 | $25,076 |
| 1979 increase in C.P.I.-13.307% | 113.307 | 113.307 | 113.307 | 113.307 |
| | $18,530 | $21,001 | $24,707 | $28,413 |
| 1980 increase in C.P.I.-12.527% | 112.527 | 112.527 | 112.527 | 112.527 |
| Gross wages adjusted for inflation through December 31, 1980 | $20,851 | $23,632 | $27,802 | $31,972 |
| Fringe Benefits | | | | |
| Payroll taxes | | | | |
| Social Security tax Max $25,900 - 6.13% | $ 1,277 | $ 1,449 | $ 1,588 | $ 1,588 |
| Unemployment Tax Max $6,000 3.4% | 204 | 204 | 204 | 204 |
| Workman's Compensation Ins. at .033¢ per dollar of salary | 687 | 780 | 917 | 1,055 |
| Health, disability, major medical and group term life insurance premiums | 800 | 800 | 800 | 800 |
| Retirement plan contribution 7% of salary | 1,459 | 1,654 | 1,946 | 2,238 |
| Total Fringe benefits | $ 4,427 | $ 4,887 | $ 5,455 | $ 5,885 |
| Total gross wages and fringe benefits disallowed for Medicaid reimbursement purposes at 1980 equivalent dollars | $25,278 | $28,519 | $33,257 | $37,857 |
| Administrative allowance permitted by Medicaid Principles of Reimbursement | 19,067 | 21,267 | 24,942 | 28,600 |
| Non-reimbursable costs | $6,211 | $7,252 | $8,315 | $9,257 |

BERRY, DUNN & MCNEIL
CERTIFIED PUBLIC ACCOUNTANTS
96 HARLOW STREET
BANGOR, MAINE - 04401
TELEPHONE 207 942-6343

# STATEMENT OF POSITION

Subject: Proposed Changes to the Principles of Reimbursement for Long Term Care Facilities and Principles of Reimbursement for ICF-MR's

Submitted to: Commissioner Michael R. Petit
State of Maine Department of Human Services

Submitted for: Public Hearing of May 6, 1981

## INTRODUCTION

Our firm renders professional services in financial and cost reimbursement matters to several nursing home facilities in Maine. Members of our firm have been involved in the health care field since the implementation of Medicare in 1966. We have served as consultants to the Maine Health Care Association (Association) on reimbursement matters since 1975 and were involved in the negotiations on behalf of the Association which led to the development of the Principles of Reimbursement for Long Term Care Facilities effective January 1, 1978.

It is on behalf of our clients in the nursing home industry and our representation of the Maine Health Care Association that we offer comments concerning certain changes proposed by the Department of Human Services (Department) to the current Principles of Reimbursement for Long Term Care Facilities and Principles of Reimbursement for ICF-MR's (Principles).

ACCRUED EXPENSES

Proposed Change:

The Department proposes to add Principle 2022.1 to both the ICF-MR Principles and the Long Term Care Principles. This new Principle requires all year end accruals to be paid within six months of a provider's year end. If they are not paid within this period, the unpaid amounts will be deducted from the subsequent year's costs.

Comment on Proposed Change- Interpretation of Current Principles

The implication of the new Principle is that an ordinary and necessary cost of providing patient care ceases to be a real cost if it is not paid in six months. Furthermore, it implies that there is some factual support for the assignment of a six month life to a valid expense. We submit that both of these implications are incorrect.

This new Principle is to be added as a sub-principle to 2020 entitled "Accounting Principles." Principle 2020 states that generally accepted accounting principles (GAAP) and the accrual method of accounting will be used to determine allowable costs in all cost reports. Principle 2021 states:

> "Generally accepted accounting principles means accounting principles approved by the American Institute of Certified Public Accountants."

Principle 2022 states:

> "Accrual method of accounting means that ... expenses are reported in the period in which they are received, regardless of when they are paid".

These sections are all consistent and adequately define when an expense is to be reported. The time of payment of an expense is irrelevant; it is when the liability for payment is incurred that determines the period in which the expense should be reported. GAAP require the accrual of any expense that has been incurred but has not yet been paid at year end. If there is an amount that is in dispute between payor and payee, GAAP requires that only the amount expected to be paid based on the facts available at the date of accrual should be accrued. If the amount subsequently paid differs from the amount originally accrued, the difference is reflected in the year of payment as an additional expense or a reduction of expense.

Accordingly, GAAP, which are specified in Principle 2020, et. al. as the basis for determining allowable costs, already prescribe the appropriate treatment of accruals. The Department's imposition of an arbitrary fixed period of six months for payment of an accrual is contrary to GAAP. The nature of each accrual and any dispute with the payee associated with the expense must govern the time necessary to execute payment. The treatment of any eventual difference between the accrual and the payment will be as the Department desires since this is already prescribed by GAAP.

The proposed Principle is not directed toward the elimination of non-allowable costs. All non-allowable costs will be eliminated from reimbursement via the application of other principles before the question of an accrued expense is addressed. This proposed Principle will affect only the reimbursement for expenses that are allowable. Therefore, the proposed Principle is punitive since it provides for the non-reimbursement of patient care costs to a provider based solely on a date of payment which is irrelevent to the determination of whether or not the cost is allowable. This proposed Principle is not directed at an abusive practice in the Medicaid program; it serves only to provide the Department with an inappropriate method to avoid reimbursing a provider for allowable costs of patient care. This is contrary to the basic foundation of a retrospective reasonable cost based system of reimbursement.

Comment on Proposed Change - Economic Impact

The proposed Principle will have the affect of creating higher costs to the Department than would occur if the Principle were not implemented. We do not believe there is a significant number of instances of accrued expenses which are not paid within a six month period to even justify the time spent to propose this Principle. However, for those few instances that may occur, they will be caused by one of two situations:

The proposed Principle is not directed toward the elimination of non-allowable costs. All non-allowable costs will be eliminated from reimbursement via the application of other principles before the question of an accrued expense is addressed. This proposed Principle will affect only the reimbursement for expenses that are allowable. Therefore, the proposed Principle is punitive since it provides for the non-reimbursement of patient care costs to a provider based solely on a date of payment which is irrelevent to the determination of whether or not the cost is allowable. This proposed Principle is not directed at an abusive practice in the Medicaid program; it serves only to provide the Department with an inappropriate method to avoid reimbursing a provider for allowable costs of patient care. This is contrary to the basic foundation of a retrospective reasonable cost based system of reimbursement.

Comment on Proposed Change - Economic Impact

The proposed Principle will have the affect of creating higher costs to the Department than would occur if the Principle were not implemented. We do not believe there is a significant number of instances of accrued expenses which are not paid within a six month period to even justify the time spent to propose this Principle. However, for those few instances that may occur, they will be caused by one of two situations:

- A lack of available cash to pay bills. The alternative would be to borrow working capital funds at current interest rates of at least 20%. If a provider can defer payment of some accrued expenses and accounts payable and incur no interest expense, or interest at a rate lower than a bank's rate, the provider is exercising prudent business judgement and minimizing the Department's expense for reimbursable costs.

- A dispute over the amount actually due a payee. This situation may occur when a product or service is defective. Often times the payor's withholding of the payment will enable the payor to negotiate a favorable settlement of the amount actually to be paid. The provider should have the flexibility to use this negotiating tool when necessary. The imposition by the Department of an arbitrary six month payment period will force a provider to pay the full amount invoiced by the payee since by doing so it is a reimbursable cost, and to not do so would change the entire expense into a non-reimbursable cost. The Department will then be deprived of any savings they otherwise could have shared by the provider's negotiation.

Summary

This proposed Principle should not be implemented. It is unnecessary since proper disposition of differences between accrued and actual payments of allowable expenses is already provided in the Principles; it will impose an unwarranted penalty against the provider since it is directed against allowable costs; it will eliminate the flexibility now available to providers regarding the timing and negotiation of payment of certain bills which now minimize the Department's total cost.

## INTEREST EXPENSE

Proposed Changes:

The Department proposes to amend the language of Principle 3032.1 regarding the definition of interest to provide that:

- Interest as a cost does not exist for funds borrowed for more than 15 months for working capital purposes. The change means that if the cost of borrowing funds is incurred for a loan with a term of 15 months or less, this cost is considered "interest expense" and is an allowable expense. If the cost of borrowing funds is incurred for a loan with a term of more than 15 months, this cost is not "interest expense" and it is not allowable.

- Except for interest incurred on the delayed payment of real estate tax bills (and then only with prior approval of the Department), interest incurred for failure "to pay accounts when due" is not "interest expense" and is not an allowable cost.

Comment on Proposed Changes - Interpretation of Principles

Neither of the Department's proposed changes indicate what the cost incurred for working capital loans in excess of 15 months, or for delayed payment of vendor bills is supposed to be if it is not "interest". There is also no support in theory or in fact for the Department's creative definition of "interest." The Department's proposed changes would impose an incorrect interpretation of the 1978 Principles on the health care industry dispite the fact that the Department's position is contrary to all regulatory precedent and economic reality. The "Notice of Agency Rule-Making Proposal" (Notice) sent to interested parties regarding the proposed change characterized it as a change to "clarify current policy on allowable interest expense..." This "current policy" exemplified by the Department's incomprehensible interpretation of the definition of interest expense represents a major change to the current Principles, not merely a clarification of policy. The notice is misleading and incorrectly states the magnitude of the change.

Principle 3031 states:

> "Necessary and proper interest on both current and capital indebtedness is an allowable cost."

Principle 3032.1 states:

> "Interest is the cost incurred for the use of borrowed funds. Interest on current indebtedness is the cost incurred for funds borrowed for a relatively short term. This is usually for such purposes as working capital for normal operating expenses."

- Principle 3032.21 states that "necessary" requires interest "Be incurred on a loan made to satisfy a financial need of the provider. Loans which result in excess funds or investments would not be considered necessary."

- Principle 3032.31 states that "proper" requires interest "Be incurred at a rate not in excess of what a prudent borrower would have had to pay in the money market existing at the time the loan was made."

Also related to the issue is Page 6 of the Principles which states under the caption "Allowability of Costs" that:

"A determination of whether or not a cost is allowable and interpretations of definitions, not specifically detailed in these principles, will be based on Medicare Provider Reimbursement Manual (HIM-15) guidelines and Internal Revenue Service guidelines in effect at the time of such determination."

On January 12, 1979, the Department issued Opinion No. 17 which stated "Interest on current indebtedness to be considered an allowable cost must be funds borrowed for a period of one year or less." This opinion, like all others issued by the Department, does not depict what the reimbursement principles and regulations authorize; these opinions serve only to reflect the Department's interpretation.

There is no support for the Department's position expressed in Opinion No. 17. The Principles do not cite twelve months, or any other number of months, within which a loan must be repaid in order for the cost associated with borrowing the funds to be interest and to be an allowable cost. Medicare regulations (Paragraph 4913 of HIM-15) are exactly the same as Medicaid Principle 3031 cited above. The Medicare definitions of "necessary" and "proper" (Paragraphs 4920 and 4927 of HIM-15) are exactly the same as Medicaid Principles 3032.21 and 3032.31 cited above. The Revenue Code and related regulations permit the deductibility of interest on any valid loan, with no limitations based on the term of the loan.

In a nursing home's appeal of a reimbursement issue involving this matter (Summit House 1978 cost report) the Department offered the Medicare regulations as a basis for its position indicating that HIM-15 provides for the disallowance of interest expense on loans with a term of more than twelve months. We obtained written confirmation from Maine Blue Cross/Blue Shield, the Medicare Intermediary for Maine, that Medicare regulations <u>do not</u> provide for the disallowance of such interest, and that interest must only be "necessary and proper" to be an allowable cost. A copy of this confirmation is included with this statement of position.

The Department's proposal now contradicts its position in Opinion No. 17 since it indicates that twelve months is not the specific term of a loan beyond which the cost of using the funds becomes something other than interest. The Department now offers the possibility that fifteen months may constitute that magic term. The magical term of a loan beyond which the cost of using the funds disipates into some unknown cost other than interest now seems to be elusive and not as easily defined as the Department would originally have us believe.

The issue of allowable interest is not and should not be related to the term of the loan. Interest is the cost of acquiring borrowed funds. The allowability of interest should be based on whether or not the interest is "necessary and proper" in the context of the definitions provided for these terms consistent with Medicare regulations as prescribed on Page 6 of the current Principles.

Comments on Proposed Changes - Economic Need for Permanent Working Capital Loans

All businesses that offer products or services to customers and allow the customer to pay for the services subsequent to their receipt must have cash funds available to pay operating expenses while they await the collection of the accounts receivable. There are four methods of obtaining these funds.

- Invested capital by the owners of a business as cash needs arise. This requires the payment of a return on the owners investment (commonly called a return on equity) in order to attract these funds. This return constitutes the cost of these funds similar to interest on borrowed funds.

- Borrowing funds from a bank and paying interest, the cost for the use of these funds.

- Generating the funds from the profitable operations of the business and retaining the annual profits for use in meeting future cash needs.

- Delaying the payment of vendor bills beyond the usual 25 to 30 day period, which entails the borrowing of vendor's funds for which the interest cost must be paid.

The nursing home industry renders services for which they do not receive payment until thirty to sixty days following the incurrance of the expense related to these services. Therefore, nursing homes have a need for funds to cover expenses while awaiting the collection of accounts receivable. The need for cash funds does not magically disappear in some arbitrarily defined number of months such as twelve or fifteen. Since the need is constant for the funds, one of the four sources of the funds must be utilized to generate them.

- Invested capital by owners is no longer a reasonable option. Even if owners had personal funds to invest, the rate of return allowed by the Medicaid Principles is only 10%. A no risk Money Market Certificate can be obtained with a 15% rate of return. The Principles discourage invested capital as an alternative to obtain necessary cash.

- In Maine 80% to 85% of the nursing home ICF patients, and 100% of ICF-MR patients are beneficiaries of the Medicaid program. This program provides for payment to providers for care rendered equal only to their allowable cost. There is no payment in excess of cost. There is no possibility to generate profits from operations, and therefore, there is no accumulation of profits as a source of providing the needed funds. Only a few of the older facilities that have enjoyed a high percentage of self-pay patients have been able fo fund their cash needs internally, and these situations are now declining.

The very regulations imposed by the Department, coupled with the fact the Department is the largest purchaser of services from the nursing homes, specifically create the need for providers to either borrow funds from the bank to meet the necessity to pay bills, or to delay the payment of vendor bills and incur the interest cost for doing so. The cost of using a bank's funds or a vendor's funds must be recognized as an allowable cost as long as the interest is "necessary" and "proper".

The proposed change will also cause banks to be even less receptive to loaning funds to nursing homes than they already are. Many financial institutions already refuse to make loans to nursing homes under current economic conditions because of their concern about the Department's whimsical approach to constantly changing the rules of reimbursement for providers. They consider the changes in general to be financially detremental to the industry, and therefore the changes impair their security for the loans.

The six to twenty bed ICF-MR facilities, who have 100% State supported patients, will have absolutely no commercial source of working capital financing available if the Principle is implemented. Their working capital need is a permanent one, since they are reimbursed only their allowable cost and do not even receive a return on equity if they are non-profit organizations. Failure to recognize this plight by the disallowance of the cost of borrowing funds in excess of fifteen months will make it impossible for an ICF-MR facility to repay the interest. Under current Principles it is already impossible for an ICF-MR to generate any funds from operations to repay the principal of a working capital loan due to reimbursement only for allowable costs. The addition of the proposed Principle will seal the financial collapse of any existing ICF-MR's and prohibit the implementation of new ones. Who will loan funds to a debtor that can not repay either the principal or interest on the loan? How are the necessary beds prescribed by the Federal Court mandate going to be provided if the cost of operating the home and obtaining related financing is not covered?

We have no objection to the disallowance of penalties as an allowable cost as proposed by the Department since a penalty is the imposition of a fine for the violation of a regulation or law as opposed to interest which is the cost of using someone else's funds. However, the remaining portions of the changes included in the proposed Principle 3032.1 must be eliminated in order to maintain some degree of consistency between economic reality and reimbursement. Proposed Principle 3036 can thus be eliminated since it will not be necessary to provide a specific exception for real estate taxes, which are no different than any other vendor bill.

## COST OF EDUCATIONAL ACTIVITIES

Proposed Changes:

The Department proposes several changes to the current Principle 4030. The primary change, however, is to limit reimbursement for educational activities to 3/10 of 1% of annual allowable costs for Long Term Care Facilities and ICF-MR Facilities in excess of 19 beds, or 1/2 of 1% or $1,500, whichever is greater, for ICF-MR facilities of 1 to 19 beds.

Comments on Changes:

To avoid the historical debate over what constitutes an allowable educational expense, we suggest the wording of proposed Principle 4032.4 be such that the prescribed percentage of allowable cost, or minimum of $1,500, is a basic allowance and not limited to actual cost.

It could then be treated similar to the "administrative allowance" with actual costs removed from total cost and the prescribed percentage or minimum added to allowable cost. This would provide operators the flexibility to choose their educational seminars to satisy licensing requirements, provide the Department with the desired control by "capping" the expenditure for this item, and eliminate the time involved by the Department for reviewing these matters.

We also suggest that the change in Principle 4032.4 be the same for both Long Term Care Facilities and ICF-MR's, and that the percentage be 1/2 of 1% for all size facilities. There is no basis for a discrepancy between different size facilities. We further recommend that all facilities have a $1,500 minimum allowance since there is no reason to discriminate against facilities in excess of 19 beds whose allowable cost could be less than a facility of 19 beds or less.

## EFFECTIVE DATE

There is no citation of an effective date for any proposed changes. The proposed changes constitute major revisions of the current Principles and should not be implemented retroactively. The effective date for any change must be specified as a date subsequent to the Public Hearing and effective for transactions incurred subsequent to that effective date .

Respectfully submitted,

BERRY, DUNN & McNEIL

By: Michael T. McNeil

Michael T. McNeil

an
ENC

APPENDIX I

BIBLIOGRAPHY

In addition to concepts, cost and statistical information provided by representatives of BMR and the Department cited previously in this report, the following documents were used as reference material. Concepts utilized in the accompanying report were abstracted from these sources.

Directory 1980 - Programs Serving the Mentally Retarded in Maine - published by Maine Bureau of Mental Retardation, Department of Mental Health and Corrections

Home and Community - Based Services Outline Material - Presented by Samuel J. Kawola, Deputy Commissioner, New York State Department of Mental Retardation and Developmental Disabilities at November 2, 1981, workshop in Augusta, Maine.

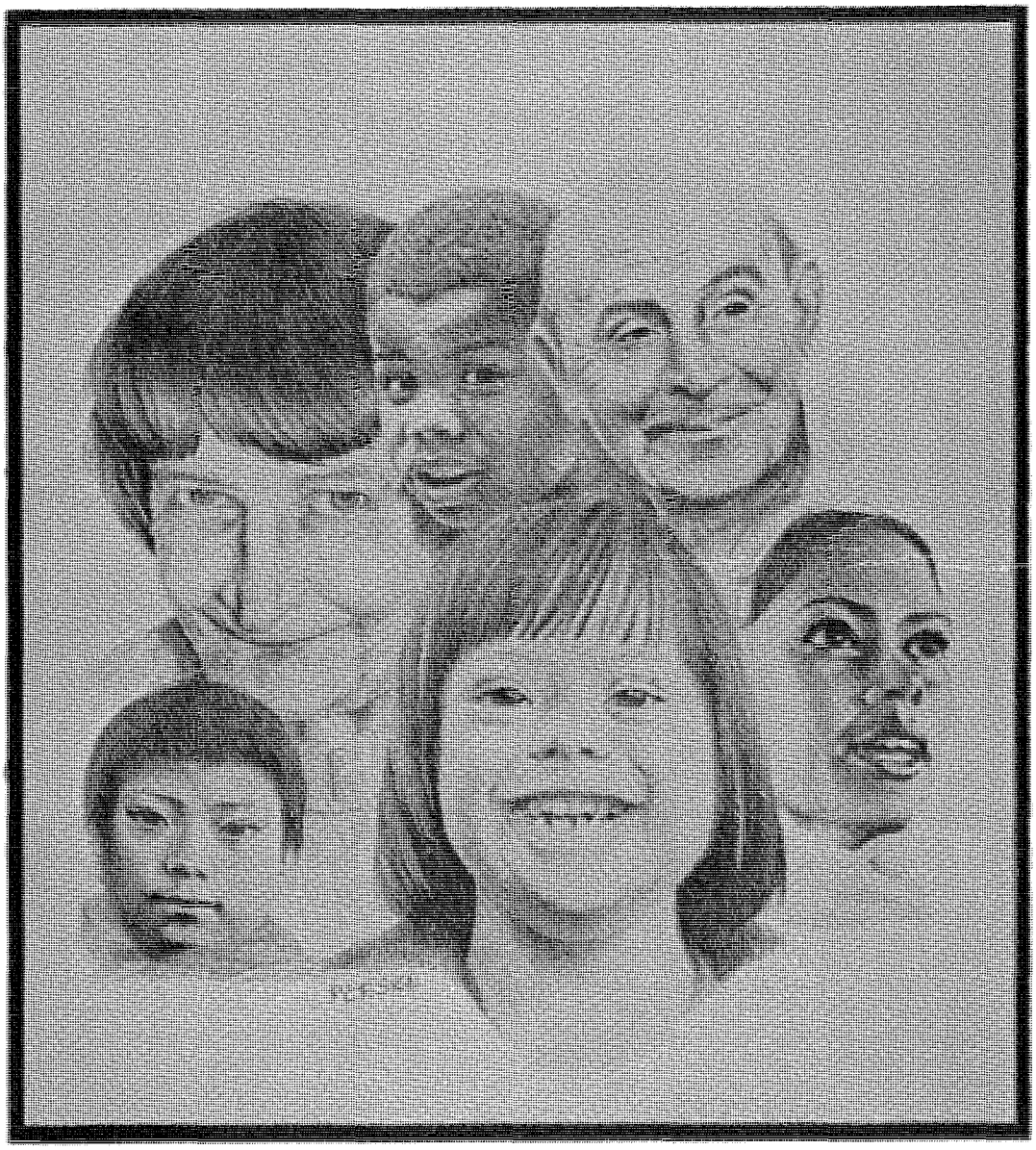
Federal Register - October 1, 1981 - Part V Medicaid Programs - Home and Community - Based Services.

National Association of State Mental Retardation Program Directors, Inc. - Intelligence Report - Bulletin No. 81-77 October 7, 1981.

Personal Care, a New Approach for Developmentally Disabled Persons - Bureau of Standards and Policy Planning, New York State

The Martti Wuori Case, Report to the Court - assembled by Lincoln Clark, Special Master, July 20, 1981

# THE MARTTI WUORI CASE-
# REPORT TO THE COURT



## MAINE'S COMMUNITIES AND THE MENTALLY RETARDED
## "much progress but more remains"

United States District Court
Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER

July 30, 1982

The Honorable Edward T. Gignoux
United States District Court
Portland, Maine 04102

Re: MARTTI WUORI, et al., Plaintiffs
v
KEVIN CONCANNON, et al., Defendants

Dear Judge Gignoux:

This is, I hope, my next to last report. So much progress has been made in the past six months that my next report may recommend that the Court terminate the Office of the Special Master and discharge the Defendants from its active supervision.

First, I would like to report that the Legislature has passed three acts to improve Maine's mental retardation system: to permit and regulate the location of group homes in residential districts, to improve due process protection relating to sterilization, and to amend the certification process for admission into public mental retardation institutions.

Very significantly, the Department of Human Services is cooperating in the preparation of an application for a waiver under the Social Security Act whereby Medicaid would cover the cost of personal care and habilitation services in the community. If granted, the rate of movement of Pineland residents to community homes could substantially accelerate.

Agreement has been reached with the Parties on requirements for recommending that the Court discharge the Defendants from its active supervision:

1. Compliance with the 15 Plans of Correction in the Stipulation Agreement of January 14, 1981.
2. Compliance with provisions of Appendix B of the Consent Decree that are not covered by the Plans of Correction, i.e., programs for specialized services for clients in jeopardy, better public relations, community integration for clients in interim programs, crisis intervention and respite care services, staff professional services and drug holidays, and full program access for clients with limited mobility.
3. Adoption of a policy for the Community Placement of Pineland Residents.
4. Satisfactory audit of compliance with Appendix B and the Plans of Correction which may be accompanied by an acceptable program to remedy any remaining observed deficiencies.
5. A satisfactory plan for monitoring Decree Standards after the termination of supervision by the Court.

The Parties have agreed to extend the term of my office from July 1, 1982 until November 14, 1982 and the Court has so ordered. To seek compliance by this date will require heroic efforts, but it can be done.

Respectfully submitted,

Lincoln Clark

Lincoln Clark

LC/st

TABLE OF CONTENTS


| PART | | PAGE |
|---|---|---|
| I. | PROGRESS | |
| | 1. Requirements for Discharge ..... | 1 |
| | 2. Community Placement of Pineland Residents ..... | 4 |
| | 3. Plans of Correction ..... | 5 |
| | 4. Personal Care and Habilitation Services ..... | 16 |
| | 5. Legislation ..... | 17 |
| | 6. ICF/MR Regulations ..... | 20 |
| | 7. Behavior Stabilization ..... | 22 |
| II. | OBSERVATIONS | |
| | 1. More and Better Community Day Programs ..... | 23 |
| | 2. Transitional Employment Programs ..... | 24 |
| | 3. Serving the MR Offenders ..... | 27 |
| | 4. Graduate Training for Case Workers ..... | 28 |
| | 5. Preventing Mental Retardation ..... | 30 |

(1) Requirements for Discharge

The Parties and the Special Master have had several meetings to formulate the requirements to be met before recommending that the Court discharge the Defendants from its active supervision:

1. Compliance with the 15 Plans of Correction in the Stipulation Agreement of January 14, 1981.

The status of compliance of these 15 Plans if presented in Section 3 of Part I of this report.

Compliance has been reached on six Plans, is very near compliance approval of five Plans, and awaits audit reports by outside professional experts on four Plans.

2. Compliance with provisions of Appendix B of the Consent Decree that are not covered by the Plans of Correction, i.e., programs for specialized services for clients in jeopardy, better public relations, community integration for clients in interim programs, crisis intervention and respite care services, staff professional services and drug holidays.

The Parties and the Special Master have identified six concerns, not necessarily deficiencies, in programs that are currently being reviewed. They are: (1) Programs for special services for clients in jeopardy: Clients in jeopardy include persons who are "doubly diagnosed" as both mentally retarded and mentally ill. Also these may include clients who need specialized services on account of sight, hearing, or mobility impairment or are MR offenders. These are discussed below in Section 7 of Part I, "Behavior Stabilization: and in Section 3 of Part II, "Serving the MR Offenders". (2) Public relations: Nearing completion is a program that provides for the establishment and central coordination of public relations activities by the six regional offices of the Bureau of Mental Retardation. (3) Community integration for clients in interim programs: In order to assist community providers in integrating mentally retarded people into community life, a comprehensive activity manual has been prepared by a team of Bureau staff under the creative guidance of Betsy Davenport and Patty Blake. This should

be particularly significant for community clients who are presently not participating in adequate out-of-home day programs. Training in the use of the manual has begun in communities around the State. The degree to which mentally retarded people are utilizing communities opportunities will be tracked through the Bureau's Management Information System and through the monitoring process included in the new Individual Program Planning Process which is provided by Plan of Correction No. 5. (4) Crisis intervention and respite care services: The status of crisis intervention and respite services will be determined by examining the intial reports of the Bureau's Management Information System. Any necessary modifications of the service delivery system will be based upon analysis of these data. (5) Staff professional services: The Bureau of Mental Retardation provides occupational therapy, speech therapy, physical therapy, and psychological services, either through its own support services staff of through contracts with professionals in these fields. In addition, many mentally retarded clients of the Bureau receive these services from the same general community providers that serve the public at large. Defendants will submit to the Special Master a statement that quantifies the professional manpower available for the above services. (6) Drug holidays: The Decree requires "that repeated administration of an anti-psychotic or antianxiety medication, including substitution of a medication of the same class, does not cumulatively exceed one year without the attending physician effecting a carefully monitored withdrawal of the medication. This periodic drug withdrawal shall be used to determine the need for continuing medication and the prescribed dosage. During such withdrawal the results shall be noted in the client's medical record. Medication may be resumed only if there is a clear documentation of benefit derived from its use. Such a drug withdrawal program shall be repeated on an annual basis."

In view of particular concern with this requirement, an up-to-date report on its implementation is to be submitted to the Office of the Special Master.

3. Adoption of the policy for the community placement of Pineland Residents:

Although a policy on community placement has been established, significant implementation awaits Federal approval of the waiver which is discussed in Section 4 of Part I, "Personal Care and Habilitation Services".

4. Satisfactory audit of compliance with Appendix B and the Plans of Correction which may be accompanied by an acceptable program to remedy any remaining observed deficiencies:

The Parties and the Special Master will appoint an outside professional expert to audit compliance with Appendix B of the Consent Decree; the charge to the auditor will be given by the Parties and the Special Master.

5. A satisfactory plan continuing monitoring:

Since the obligation of the Defendants to comply with the provisions of the Consent Decree continues indefinitely, a plan must be developed to provide for monitoring compliance after the Court releases the Defendants from active supervision. The Parties and the Special Master are working to reach agreement on such a Plan. The principal issues remaining to be resolved are determining the best procedure for selecting a monitor to insure that only professional considerations will be weighed in his/her selection, and the method for establishing the areas for review.

(2) Community Placement of Pineland Residents

The major remaining deficiency that must be corrected in order for the Court to discharge the Defendants is the slow rate of movement of residents out of Pineland into the community. All residents are receiving diagnosis, evaluation, and habilitation planning, and, where appropriate, are being prepared for movement to the community. The readiness of residents for discharge is reviewed quarterly. Of 340 residents, about 64 were discharged in the period between July 1, 1981 and June 10, 1982, and 6 died. About 57 are deemed ready to move now; in fact, they have been ready to move for a long time. Approximately 120 additional residents have also been recommended for community placement over the next one to two year period. It is anticipated that these needs can be met within the next three years.

The delay in movement is caused by the lack of suitable openings in the community. In the past six months 47 openings were created, but during the same period 18 boarding care beds were lost because of closures that could not be replaced because of the moratorium on the establishment or replacement of boarding home beds. The State is about 158 openings behind the schedule stipulated in the Consent Decree.

The creation of an opening in a community facility does not mean that a place is automatically available for a Pineland resident. Some of the 1,000 clients of the Bureau of Mental Retardation who are currently in community homes throughout the state receive priority over Pineland residents for new openings, sometimes because their need is greater and sometimes because the community home is better suited for their needs.

Initiation of the personal care and habilitation services program discussed in the next section would accelerate community placement of Pineland residents.

A policy governing the community placement of Pineland residents has been developed.

(3) Plans of Correction

In order to deal with the deficiencies perceived in the community mental retardation system, the Parties reached a Stipulation Agreement on January 14, 1981 in which the Defendants agreed to develop fifteen "Plans of Correction". Once developed and implemented, these Plans of Correction would be "systems of compliance" that would aid in achieving full compliance with Appendix B of the Consent Decree.

The status of the fifteen Plans has been reviewed monthly in meetings of the Parties with the Special Master. To date, six of the Plans of Correction have been found to be in compliance, five Plans are very close to final approval, and action on the four remaining Plans awaits audit by outside professional experts. Six of the Plans have been deemed not to require audits by outsiders and five Plans (Nos. 1, 2, 3, 4 & 7) have been audited by Dr. Vernon P. Patterson. His credentials are:

> Associate Professor of Psychology and Director, Division of Human Services, University of New England
>
> Faculty Supervisor, Apprenticeship Program, Pineland Center
>
> Advisory Board Member, Down East Chapter of the National Remotivation Therapists Organization
>
> Former Certification Advisory Committee Member, State Board of Education
>
> B.A. University of Maine, Orono; M.S., Ph.D. University of New Hampshire
>
> Brother of a person with cerebral palsy and mental retardation

A summary of the Plans of Correction and their status follows:

Plan of Correction No. 1: All clients shall be removed from Seven Elms Boarding Home, Willowcrest Boarding Home and Hilltop Boarding Home. Status: Seven Elms Boarding Home -- All clients have been removed. Willowcrest Boarding Home -- All but two clients have been removed. The two who remain are doing so with the concurrence of their Interdisciplinary Team. Hilltop Boarding Home -- All but one client has been removed. That one is remaining because of family preference.

Conclusion: After review of the auditor's report, the Parties and the Special Master concur that compliance with Plan of Correction No. 1 has been achieved.

Plan of Correction No. 2: After an evaluation of the residential and program services provided at Ward's Home, Pinkham's Home, and Northland Manor, all clients shall be removed or offered suitable programs.
Conclusion: After review of the auditor's report, the Parties and the Special Master concur that Ward's Home and Northland Manor are in compliance.

After review of the auditor's report, the Parties and the Special Master concur that a compliance statement on Strong's Children's Home (formerly Pinkham's Home) should be deferred until the cottage renovations have been completed, programming is in place, the PETs have determined the lentgh of the programming year (full time in all appropriate cases) and community integration has been documented. The final audit of Strong's Children's Home is scheduled for late in September.

Plan of Correction No. 3: The population shall either be reduced or the level of programming for clients shall be increased at the under-listed homes: Bruce Haven, Hall-Dale Manor, Tissue's Boarding Home, Noyes Boarding Home and Houlton Residential Center.
Status: Bruce Haven -- One class member remains. Legal guardians have waived BMR services. Hall-Dale Manor -- There is a signed agreement to improve programming; off-site programming and in-home programming are available. Tissue's Boarding Home -- Two class members remain. The guardian of one has waived BMR services and the guardian of the other is considering alternate placement of waiving services. Noyes Boarding Home -- Record keeping needs improvement. Houlton Residential Center -- There is a signed agreement to improve services. Off-site programming is available. Inservice training is documented. While the physical layout is not optimal, steps have been taken to make the facility more attractive. More attention should be given to the clients' rooms. HRC's client records are very complete.

Conclusion: After review of the auditor's report, the Parties and the Special Master concur that compliance with Plan of Correction No. 3 has been achieved.

Plan of Correction No. 4: A case review will be conducted for all clients in nursing homes that serve predominantly non-mentally retarded individuals. Upon completion of the case review, clients recommended for replacement shall be moved. Clients not recommended for replacement shall be reviewed by an on-site professional team for purposes of recommendations to upgrade programming.

Auditor's Finding: The Bureau carried out the individual case review, compiled a list of clients recommended for movement, developed regional plans to meet client needs, and moved clients within the provisions of Appendix B. Concerns arise when, due to the lack of alternative placement sites, interim plans for those not yet moved are evaluated. Many of these nursing homes are inappropriate because of their size. In addition to their size, the activities staffs are oriented to the geriatric population and not to the mentally retarded population. This leads in many cases to activities designed for the elderly being substituted for programming appropriate for a mentally retarded individual. It was not uncommon in the auditor's experience to hear a nursing home staff person say that the client does everything our other clients do. There also seems to be a reluctance by nursing home staff to request inservice training from BMR. The auditor recognizes the difficulty BMR has had finding appropriate placements and encouraging ICF/MR-nursing development. However, with a few exceptions such as Oceanview, the auditor would discourage reliance upon the nursing home placement as an ongoing alternative, the auditor makes the following recommendations: (1) Utilize nursing homes when age appropriate and the client has voluntarily resigned from off- and/or on-site programming. (2) When programming is an IDT recommendation, only those homes with access to off-site programming should be considered. (3) When the only programming appropriate is on-site programming, the hiring of a one-to-one social service

worker should be part of the IDT recommendation. (4) The BMR could be much more assertive regarding the appropriate inservice training for nursing home staffs. Initial or continued placement could be made conditional upon completed inservice training by nursing home staff. (5) The urgency for additional community placements should be reduced until existing needs have been met.

Conclusion: After review of the auditor's report, the Parties and the Special Master concur that compliance with Plan of Correction No. 4 has been achieved. BMR will prepare a response to deal with the auditor's findings. In discussing the auditor's findings, the possibility of establishing active developmental treatment programs for mentally retarded residents of general ICFs was pursued. This is apparently a service option available under Medicaid but untapped in Maine. The Bureau of Mental Retardation should continue its negotiation with the Department of Human Services to make this service available as soon as possible.

Plan of Correction No. 5: After a case record review, the Prescriptive Program Planning process shall be re-examined, and when necessary, re-structured. A consultant has been employed to undertake the review and make recommendations.

Status: The Defendants' Prescriptive Program Planning process has been approved except for one element -- the proper policy on one-to-one care, which is still under consideration.

Plan of Correction No. 6: The impact of the revised Prescriptive Program Planning process shall be statistically evaluated and further revised in accordance with the evaluation.

Status: A report on this Plan is scheduled for submission in October.

Plan of Correction No. 7: The BMR shall assist the Consumers Advisory Board in making trained correspondents available for participation in the IDT meetings of all clients who are not able to advocate on their own behalf.

Auditor's Findings: BMR has in the majority of cases identified all class members needing a correspondent. BMR has assisted to some degree the CAB in the recruitment of correspondents. The avenue of utilizing the college student population as correspondents has not been pursued based on the inherent transience of the college population. BMR has provided one State-wide and one regional training program for correspondents. CAB has recently sent out a correspondent self-evaluation review survey. Some correspondents report that they were "volunteered" without their knowledge or permission. Some correspondents report being ill-received at IDT's. The majority of correspondents have not received training by BMR. The most frequent notation on class member IDT cover sheets is "correspondent notified - did not attend". The CAB membership present during the audit interview voted (with one abstention) that the Defendants were not in compliance with stipulation paragraph No. 7 or Appendix B of the Consent Decree. The auditor found the Defendants not in compliance with Plan of Correction No. 7.

Conclusion: In consideration of the above concerns, the auditor concluded that the Defendants were not in compliance. After conference with the Parties it became clear that technical compliance of Plan of Correction No. 7 had been achieved. Because they agreed that the deficiencies noted in the auditor's report should be dealt with, the BMR, with input from the Consumers Advisory Board, has drafted and submitted a program to the Special Master.

Plan of Correction No. 8: This Plan stipulates that the Defendants shall retain a consultant in vocational programming to evaluate, relative to Decree compliance, the programs of: Bangor Regional Rehabilitation Center, Goodwill, Coastal Workshop, Pathways, Winthrop Work Activity Center and Green Valley, and thereafter formulate plans to bring these programs into compliance with the Decree.

Status: The Consultants' report by Adrian Levy, Roger Deshaies, and Joe Ferri was submitted on December 7, 1981. It provided the basis for reaching agreements with the six specified agencies and also for formulating a set of State-wide recommendations to improve the coordination, development and appropriateness of vocational services to mentally retarded persons in areas where the individual agencies would be unable to effect the needed changes.

These recommendations were referred to a Task Force composed of Chris Gianapoulis (Governor's Committee on Employment of the Handicapped), Kevin Baack (Goodwill), Joel Packer (Pathways), Richard Tripp (Bureau of Rehabilitation), Jim McBrian (Coastal Workshop), and Bob Foster (Bureau of Mental Retardation). Their preliminary report was reviewed by Bureau directors and staff and by the Plaintiff's attorneys. A final draft was jointly submitted by Ronald S. Welch, Director, Bureau of Mental Retardation and C. Owen Pollard, Director, Bureau of Rehabilitation, on June 15, 1982.

In a letter dated July 13, 1982, the attorneys for the Plaintiffs stated their opinion that the plans for carrying out five of the twenty-one recommendations in the State-wide report are deficient. The criticized recommendations were:

Funding Recommendation #4: That provider and public agencies assume a leadership role through the Maine Sheltered Employment Association in arranging workshops, training and other technical assistance in order to expand community/private sector support.

Funding Recommendation #5: That State funding sources plan an active role in Recommendation #4 (above) to include, if necessary, identification of financial and other support which might be obtained from Federal/State programs and from cooperating private sources.

The Defendants have agreed to fund the implementation of these recommendations at an initial level of $22,500 under the administration of an advisory board chaired by Chris Gianopoulis, with representation from the Sheltered Employment Association and the Rural Cooperative. Additionally

the BMR will fund modest demonstration grants to encourage innovative design, production, and marketing efforts.

The Plaintiffs' attorneys question the adequacy of the funding and the capacity of the agencies themselves to initiate needed design and marketing efforts.

Staffing Recommendation #1: That direct service staff have at least a Bachelor's Degree, unless specialized long-term experience warrants waivers.

The Defendants are establishing a Task Force to review the required qualifications of staff, with the specific charge to consider raising the minimum education requirements for staff in work activities, work adjustment training, sheltered employment, and vocational skills programs.

The Plaintiffs' attorneys hold that further review is unnecessary and that this recommendation should be implemented forthwith.

Staffing Recommendation #4: That continuing attention be given to insure that facilities are accessible under Chapter 504 and that efforts are made to recruit and employ handicapped persons.

The Defendants plan to offer Joint Training Sessions relative to Chapter 504 and to seek resources for donated labor and materials to assist agencies in making minor modifications to ensure accessibility.

The Plaintiffs' attorneys criticize the lack of a plan to make program sites accessible to the physically handicapped.

Vocational Evaluation Services: The consultants' report contains several recommendations relating to comprehensive vocational evaluations for all clients.

The Plaintiffs' attorneys submit that instead of developing a plan to provide the evaluations, the Defendants have only agreed to initiate an extensive procedure to confirm the need to do the evaluations.

Special Master's Conclusions: The Special Master applauds the Defendants for reaching agreements with the specified agencies, which is one of the purposes of Plan of Correction #8. While the Defendants' State-wide plan,

if carried out, will greatly improve the quality of vocational services to mentally retarded persons, incorporation of the proposals of the Plaintiffs' attorneys would further improve the quality of vocational services and would expedite their delivery.

The Special Master does not share the optimism of the authors of the State-wide plan, but for different reasons than those of the Plaintiffs' attorneys. While the plan would improve the services of the sheltered workshops by strengthening their weaknesses, it capitalize insufficiently on their special strengths. The dedicated staffs of the sheltered workshops know how to teach good work habits -- getting to work on time, punching time-clocks, following instructions, taking coffee and luncheon breaks, cooperating with fellow workers. It must be recalled, however, that workshops are but one element in the continuum of day programs. Workshops should be encouraged to graduate clients to transitional employment programs in existing Maine manufacturing, retailing, and service industries, with particular emphasis on the health industry. While sheltered workshops know how to teach work habits, established industries have more "know how" to teach the work skills needed in the specific jobs for which the mentally retarded are qualified. "Sheltered workshops within industry" assure that the client/workers will be paid in accordance with their productivity, eliminating the need for social security, Medicaid and housing subsidies for some. Even more important, a job in an established industry creates the psychological satisfaction of "having made it" in the competitive world.

The Federal government offers tax incentives to encourage industries to cooperate in employing handicapped workers. The BMR and BR could do much more to provide incentives for establishing "sheltered workshops within industry".

Final action on this Plan is scheduled for the August meeting with the Parties.

Plan of Correction No. 9: Defendants shall develop an instrument to identify unmet residential and programmatic client needs, by type and location. This instrument shall be utilized to determine and aggregate these needs, and to develop a plan for resource realignment or development where necessary.

Status: The Plan contemplated under this Agreement has been in the course of development throughout this Special Master's tenure and is clearly the most critical of the Plans in that it provides the means for achieving the Decree's overriding purpose of assuring meaningful community living and appropriate programming for the Decree's beneficiaries. It also provides the means for developing the community resources that Pineland residents (see Plan of Correction #15) will require in order to receive the placements they have long deserved.

The needs assessment was completed in April 1981 and was revised in October, 1981. The Management Information System (see Plan of Correction #12) is in operation and revised data will soon be available. The Defendants have, during this period of time, taken advantage of whatever opportunities have arisen to develop appropriate residential and program resources but clearly much more needs to be done (see Part I, Section 1 on "Community Placement of Pineland Residents").

When the Plan for development is finalized and adequate funding is available through Medicaid and other sources, it is anticipated that development will move ahead swiftly. While the actual development cannot be completed in less than two to three years, active court involvement should not be required after the Plan is completed and audited, and funding is assured.

Action by the Parties on it is deferred pending audits by outside professional(s) of this and Plan Nos. 12, and 13.

Plan of Correction No. 10: A plan shall be formulated by designated representatives of the disciplines of psychology, occupational therapy, physical therapy, and speech therapy to recruit, develop and utilize the professional resources of their State and National organizations for the benefit of the Decree's class members.

Status: Final approval is awaiting review of an addendum dealing with one aspect of the Plan.

Plan of Correction No. 11: Quarterly reports shall be made on problems and progress toward the alleviation of deficiencies in the following areas: transportation, crisis intervention, family support, respite services, and community recreational opportunity.

Conclusion: The quarterly reports have been made. The Parties and the Special Master have agreed that an audit of this plan is not needed. Reports of the regional public relations coordinators will be incorporated in future quarterly reports. The Parties and the Special Master concur that compliance with Plan of Correction No. 11 has been achieved. (Regarding crisis intervention and respite services, see Part I, Section 1 of this report.)

Plan of Correction No. 12: A plan shall be formulated to track clients' needs and for resource development.

Status: The Defendants have developed and implemented a computerized management information system in response to Plan of Correction No. 12. Action by the Parties on it is deferred pending audits by outside professional(s) of this and Plan Nos. 9 and 13.

Plan of Correction No. 13: A plan shall be developed to improve monitoring systems of services delivered to clients, to assure the quality of the services and to provide for prompt identification and correction of the deficiencies.

Status: Action by the Parties is deferred pending audits by outside professional(s) of this and Plan Nos. 9 and 12.

Plan of Correction No. 14: A plan shall be developed for training all employees and service providers to meet Decree standards and the purposes of the several Plans of Correction.

Status: This plan has been agreed upon by the Parties and its implementation has begun. It is to be audited by Dr. Vernon Patterson.

Plan of Correction No. 15: Pineland Center shall re-establish its Planning Committee to ascertain the best suited community placement for each current resident and transmit its findings to the BMR for incorporation in a long-term community development plan.

Status: This plan has been developed and is being incorporated into the BMR's State-wide development plan by the Defendants as required by Plan of Correction No. 9. The Parties and the Special Master have concurred that compliance has been achieved.

(4) Personal Care and Habilitation Service

In the past six months, possibly the most important step to improve Maine's system for the mentally retarded was the decision communicated on April 9, 1982, by Michael R. Petit, Commissioner, Department of Human Services, inviting the Bureau of Mental Retardation to prepare a formal request to waive Federal Medicaid regulations and allow Maine's Medicaid Plan to include coverage of services of therapeutic foster homes, personal care homes, and day habilitation for mentally retarded individuals.

Nine states have already received such waivers and Maine will soon join twenty other states whose applications are pending in Washington.

A preliminary survey at Pineland Center identified 60 persons who might be suitably placed in therapeutic foster homes. A presently unknown additional number are transferable from community ICF/MRs. Therapeutic foster homes represent a distinct benefit for a number of mentally retarded persons over traditional foster homes for some clients. Predictable benefits include: (1) improved program quality, (2) more spaces for more clients from Pineland Center and less appropriate community residences, (3) greater accountability of providers, through training and certification, (4) better community integration of the mentally retarded, (5) more rapid development than the two to three years required to develop community ICF/MRs and, (6) homes and day programming for three persons at about the same cost as for one institutional or community ICF/MR placement.

It is projected that the waiver will yield between 250 and 275 new personal care beds and as many day habilitation openings within the first year of implementation. Additional services will be developed in subsequent years.

(5) Legislation

Maine has made remarkable progress on the Legislative front. In its last session the Legislature overwhelmingly passed the four bills proposed by the Bureau of Mental Retardation: (1) Budget -- a bill to increase the budget of the Bureau of Mental Retardation; (2) Sterilization -- a bill to improve due process protection in sterilization; (3) Zoning -- a bill to facilitate the establishment of small group homes for the mentally retarded in residentially zoned districts; and (4) Certification -- a bill to improve and simplify the procedure governing the admittance of mentally retarded clients to state institutions.

Budget: Much credit is due Governor Brennan and the Maine Legislature for its emergency appropriation of $1.5 million to the Bureau of Mental Retardation for the continued development of homes and programs for Maine's mentally retarded citizens. This financial commitment is indeed a manifestation of the moral commitment Maine people have for the mentally retarded of this State.

Sterilization: The "Due Process in Sterilization Act of 1982" is the result of long study and review. It recognizes that legal safeguards are necessary to prevent indiscriminate and unnecessary sterilization and to assure equal access to desired medical procedures for all Maine citizens. Here is a summary of the Act's provisions:

Prior to initiating sterilization procedures a physician shall obtain the informed consent of the individual or the authorization of the District Court. A Court order authorizing sterilization is required for persons: under age 18 years and not married or otherwise emancipated; presently under public or private guardianship or conservatorship; in a state institution; or not having given consent to a physician. Such persons shall be represented by legal counsel and, to determine a person's competency to give informed consent, the Court shall appoint not less than two disinterested experts, including at least one licensed psychologist or psychiatrist. If the Court

determines that a person is able to give informed consent but does not consent, it shall issue an order forbidding sterilization of that person. If the Court determines that a person is not able to give informed consent, the Court shall forbid sterilization unless it determines that sterilization is in the best interest of the person. Criteria for determining that sterilization is in the best interest of a person include: if less drastic contraceptive methods have been tried or are believed to be unworkable or inappropriate; if there is a medical statement challenging the psychological capability of the person to procreate; and if there is a medical statement predicting that the life or health of the person could be threatened by procreation or child rearing. If the Court finds that sterilization is in the best interest of the person, the sterilization procedure shall be the most reversible procedure which in the judgment of the physician is not inconsistent with the health or safety of his patient. The bill does not require any hospital or person to participate in performing any sterilization procedure, and makes any physician, psychiatrist or psychologist acting nonnegligently and in good faith in his professional capacity immune from any civil liability. Finally, the bill establishes a six-person committee to review annually the authorizations of sterilization, to assess the need for any changes in the procedures or standards.

Zoning: In order that mentally retarded or developmentally disabled persons should not be excluded by municipal zoning ordinances from the benefits of normal residential surroundings, the Legislature established that "community living use" shall be considered a permitted single-family use of property for the purposes of zoning. "Community living use" means a state-approved group home for up to eight mentally handicapped or developmentally disabled persons. A municipality's zoning board of appeals may hold a public hearing on the application for such a zoning permit and may modify or disapprove the application if the use would: create or aggravate a traffic hazard; hamper pedestrian circulation; not permit convenient access to commercial shopping facilities, medical facilities, public transportation,

fire or police protection; not be in conformance with the applicable building, housing, plumbing and other safety codes, including minimum lot size and building set-back; and, if the proposed community living use would be within 1500 feet of an existing community living use or would result in the excessive concentration of these uses within the zone or municipality. While there is risk of local misinterpretations of the spirit behind the permitted grounds for disapproval of application, this bill should substantially help to overcome the long-standing opposition of a few localities to the establishment of community use facilities.

(6) ICF/MR Regulations

In my January report I stated that there are inconsistencies between the provisions of the Consent Decree and the program regulations, principles, and practices governing Intermediate Care Facilities of the Mentally Retarded which should be rectified.

Principles of Reimbursement for ICF/MRs have been rewritten and put into effect by the Maine Department of Human Services as of July 1, 1982. This was done after consultation with the Bureau of Mental Retardation, the Maine Health Care Association, and the Maine Association of ICF/MR Providers.

The major changes in these principles are:

Interim Prospective Rates: The DHS will issue each facility its "interim prospective rate" prior to the beginning of its fiscal year. This rate includes an inflation factor of 7.9 per cent for the fiscal year ending June 30, 1983.

Change in Chart of Accounts: The new Principles segregate all operating costs into two categories, "fixed costs" and "variable costs". Fixed costs are defined as: depreciation of buildings, fixed and movable equipment, motor vehicles, and land improvements; amortization of leasehold improvements; real estate taxes; real estate insurance premiums, including liability and fire insurance; interest on long-term debt; return on equity capital for proprietary providers; rental expenses; amortization of finance costs and start-up costs; motor vehicle insurance payments. Fixed costs will be paid on a retrospective basis similar to the current reimbursement system.

All other costs are considered "variable costs" and will be paid based on the interim prospective rate.

The main effects of the changes are to increase administrative allowances, provide for cost of living increases, and provide incentives for efficient administration.

As a separate issue, the BMR is pressing for an increase in the day program rate.

Also underway is a review for the purpose of simplifying those regulations which experience indicates have not contributed to the health, safety and active treatment of clients, or appear to be in conflict with the principles of the Consent Decree.

(7) Behavior Stabilization

Individuals with both mental illness and mental retardation present a difficult challenge for those charged with responsibility for their care. A task force composed of the directors of the Bureau of Mental Health, and the Bureau of Mental Retardation, regional staff from the Bureau of Mental Retardation and superintendents of the Bangor Mental Health Institute, Augusta Mental Health Institute, and Pineland Center is addressing this long-standing problem. The task force is working to identify the group of individuals who traditionally have "fallen through the cracks", to define the service needs of this population, and to determine the best ways to meet their needs.

Services for this group are currently provided in a number of uncoordinated ways. The task force will make recommendations that will fix the responsibility for their care and suggest a number of treatment alternatives, with the goal of developing a full continuum of care over the longer term.

In addition, the Superintendents of Augusta Mental Health Institute, Bangor Mental Health Institute, and Pineland Center are meeting to identify and recommend individuals who are now housed in their facilities who could be transferred into the new program upon its development.

Finally, the Behavioral Stabilization Unit planned for Pineland Center will become part of the system of care and treatment being developed for this underserved population. Guidelines and specific criteria for the Behavior Stabilization Unit are being developed.

OBSERVATION #1: More and Better Community Day Programs

Beneficial though de-institutionalization may be for clients and the community, it breaks down if good day programs are not available. There are a great variety of day programs in Maine. The Bureau of Rehabilitation and the Bureau of Mental Retardation have labored long and creatively to develop "Inter-agency Standards for Adult Community Programs". This publication represents a major "engine of compliance" to satisfy the requirements of the Consent Decree.

Like other organizations, day programs may have organizational and staffing problems, but these are usually less significant than the financial and "system integration" problems. Partial solution of the financial problems will be resolved when the Federal government grants Maine the right to apply Medicaid funds to cover a greater part of the costs. In addition, the Department of Human Services is currently reviewing various schedules that would result in quite substantial increases for many day programs serving residents of ICF/MRs. A schedule of increased rates is due to go into effect about October 1, 1982. The day programs also need incentives to stimulate local community financial support.

The system integration problem relates to the position of day programs in the continuum of training offered to the mentally retarded. There is now little incentive to graduate clients from one day program to a more advanced day program, or on to competitive employment. Currently underway is a study of a representative sample of day programs that is designed to shed more light on solutions of their problems. The results will be presented in the next report of the Office of the Special Master.

OBSERVATION #2: Transitional Employment Program

For many years, the vocational training sequence has included a vocational evaluation, work adjustment training and placement into a sheltered workshop or competitive job. For the majority of mentally retarded adults this sequence has ended in many years of sheltered employment within existing rehabilitation facilities. This means years of acquiring generalized work skills that are often not transferable to particular job openings in the competitive job market. In addition, the perception that mentally retarded individuals perform poorly in outside jobs, productivity is low, quality of work is erratic and attendance is poor, has led many businesses to shy away from hiring developmentally disabled individuals. This perception by the business community is reinforced when individuals are trained in rehabilitation facilities rather than in existing factories and business establishments.

The vocational training sequence has changed in recent years throughout the country, and in the state of Maine in the last year. The Hospital Industries Program at the Maine Medical Center is a splendid example. The Maine Medical Center, through a grant funded by the Bureaus of Mental Retardation and Rehabilitation, has established a vocational skills training and sheltered workshop in the dishwashing area and assembly line of its food services department. Its intent is twofold: (1) to offer training and services that focus upon an identifiable vocation or occupation, and to develop the specific skills that are necessary to perform this vocation or occupation; and (2) to offer individuals the opportunities to acquire appropriate skill development so they can: (a) work toward employment at the Maine Medical Center on a full time basis, (b) work toward the development of skills transferable to other areas of the hospital or to facilities outside the Maine Medical Center, and (c) demonstrate to the employment community the ability of disabled individuals to achieve equal productivity through job sharing.

Twenty disabled individuals have been hired through this program either on a full or part time basis. The quality of their work has been

excellent, their productivity has been steadily increasing, and their attendance has been exceptional. "They don't drop as much silverware down the garbage disposal as our regular employees." Further, the Food Services Department and the Maine Medical Center have seen a financial savings because of this program. The turnover rate, traditionally high in this department, has been reduced substantially, resulting in reduced need for advertising, interviewing, orientation, and overtime. The disabled individuals, are in fact members of the team of the Maine Medical Center. They receive a M.M.C. check, they are eligible for M.M.C. benefits. They become members with I.D. numbers of the Maine Medical Center employment group. They are not identified with a "Sheltered Workshop", but rather with the M.M.C. and its other 3,000 employees. The impact on the self-image of these employees is significant. Because of past experiences these retarded individuals never dreamed of holding a full time job with full benefits, without the "stigma" of being labeled retarded. They are productive citizens now, and paying their way! The dedicated staff of the program, as well as the leadership provided by the Maine Medical Center, should be applauded for their efforts to provide transitional employment opportunities to severely disabled adults.

The future of transitional employment in general and in the health care area specifically, is wide open. Maine Medical Center has established through a detailed job analysis a model for duplication. It is realistic to assume that in the next twelve months, through a joint effort of the Bureaus of Mental Retardation and Rehabilitation, and with technical assistance from the Hospital Industries staff that eighty developmentally disabled individuals will be hired through similar transitional employment programs in five hospitals in the southern part of the State. Duplication of this program should be encouraged State-wide; this could give hundreds of disabled individuals the opportunity to work and earn a good wage in a normal environment.

Launching the Hospital Industries Program at the Maine Medical Center has required a lot of work. Some experts argue that it is easier to make ten placements of two clients than one placement of twenty clients as at

the Maine Medical Center. This may be especially relevant in smaller communities. Many sheltered workshops could develop such programs in conjunction with private industry. Just as the Federal government offers tax inducements to make it worthwhile for established industries to participate in "sheltered workshops in industry", the State government should make it worthwhile for the existing sheltered workshops to lead the way.

OBSERVATION #3: Serving the MR Offenders

Since January there have been many staff conferences on how best to deal with the problem of habilitation programs for MR offenders.

The summary of the problem and alternative solutions contained in my January report is repeated:

> "An often ignored group of the mentally retarded is "MR Offenders" who have been committed to correctional institutions. Because criminals are not tested for mental retardation, we do not know how many there are in Maine, but it is estimated to be at least 40. Their judicial commitment causes them to lose their civil rights but not their Decree rights. They are not receiving the habilitation services that they ought to have.
>
> MR offenders are not being offered habilitation programs because they are distributed among several correctional institutions. Servicing them where they are would be very complex and expensive. Concentrating them in a single correctional institution would simplify the problem, with program staff and program services provided by Pineland Center staff or the Bureau of Mental Retardation.
>
> Another alternative that merits exploration would be the creation of a small secure facility at Pineland Center. The Department of Corrections would provide the security staff, and Pineland Center would provide programs and support services. Implementation of a program for the MR offender will require careful planning and the cooperation of the Departments of Correction, Human Services, and Mental Health and Mental Retardation. Statutory changes will also have to be considered. It is worthwhile to plan for this special group, to try to salvage some of them to lead useful lives after they are released back into the community."

Defendants are preparing a legislative request for the establishment of a discrete program for adjudicated mentally retarded offenders. The program will be based on the experiences and expertise of those few states that have ventured to serve this otherwise untreated population of mentally retarded persons.

OBSERVATION #4: Graduate Training for Case Workers

Outside of the major cities of Maine there is a shortage of trained graduate social workers, particularly those qualified to work with the developmentally disabled. This can be explained in part by the lack of opportunity in Maine for graduate studies in social work. This issue has been examined before, but in light of the development of community homes and services for more of Maine's handicapped it is appropriate to take another look at the extent of the need.

There may not be sufficient justification to establish a full-scale residential graduate school of social work in Maine right now, since full-time students can go out of state. There are, however, many case workers, child development workers, human service workers, and geriatric workers, who are handicapped in competing for those positions which require a Master's Degree in Social Work. In addition, time and money prevent many of these dedicated workers from participating in the programs of universities in other states. The nearest is in Concord, New Hampshire. The result is that many of the families and clients do not receive adequate professional service.

The Consent Decree creates a demand for graduate education in social work. It specifies that a sufficient number of intermediate and advanced courses be offered so that each staff person could receive 50 hours of training in any six month period; the requirement may be met by satisfactory completion of relevant course work at a university. This provision was placed in the Consent Decree to ensure a high quality of case planning, family support, and client social work.

There is a growing determination to develop a full graduate education program in social work in Maine. The University of Connecticut will be offering more required courses in Maine this fall, including four courses to be given in the Augusta area, where the Department of Mental Health and Mental Retardation will provide the necessary space and equipment.

The University of Maine, the proper institution to offer an expanded graduate program in social work in Maine, has thus far failed to show interest in organizing such a program. Consequently, a group has been meeting with officials of the University of New England to investigate the possibility of establishing a Master of Social Work program. The group has agreed to gather basic information, e.g., previous needs assessment material and application procedures for accreditation by the Council of Social Work Education. The University of New England has an excellent "track record" in providing needed programs in Maine, having already established a medical school and training programs in occupational and physical therapy.

It is reasonably predictable that Maine will have in the near future a graduate program in social work -- launched by the University of Connecticut, and continued by the University of New England, or by the University of Maine as a late starter.

OBSERVATION #5: Preventing Mental Retardation

Mental retardation is a condition of many types and causes. Two types of programs are needed -- treatment and prevention. Maine has won many battles to improve the treatment of the mentally retarded but Maine is losing the war against mental retardation. The major goal now should be prevention, not just better care of victims.

The issue was dramatized to me when I talked to experts on mental retardation in India a few months ago. India has about 15,000,000 mentally retarded compared to Maine's 30,000 -- or five hundred times as many. India has some day programs in major cities but practically no residential programs, it can't afford them. So, India is allocating its MR resources primarily to prevention. This is sound policy. By contrast, Maine's MR resources are going primarily for care and treatment -- at substantial cost. No price can be put on the anguish of parents of a mentally retarded child, especially when mental retardation could have been prevented. The public is generally unaware of the cost of neglect. When a child born in Maine is so retarded that he/she requires intensive, life-long care and treatment, the cost for an average life span of 72 years at present estimates of $36,000 per year, is $2,592,000. Any program that prevents even one case of mental retardation is worthwhile.

The development of a preventive program begins with consideration of the causative factors. They fall into five main categories:

1. Genetic Factors

About 20% of the severe and profound cases of mental retardation are determined by genetic factors. For many conditions, for example, metabolic errors and chromosome anomalies, amniocentesis provides an accurate prenatal diagnosis. Women may be subjected to amniocentesis because they or their husbands are known to be carriers of genetic defects or because they are old for child bearing. The findings may indicate that prevention would require termination of the pregnancy, but social attitudes often preclude this solution.

Adopting modern techniques of pre-natal diagnosis is a long-term program but for the present, genetic counselling and family planning can help prevent such problems as those connected with single gene disorders and chromosome anomalies.

2. Chemical and Physical Agents

Vigorous and sustained public health measures are needed to prevent retardation caused by pollutants like mercurials and lead.

Nutrition and maternal and child health programs must also be strengthened. Proper diet for the mother during pregnancy, and breast feeding for the child in the early years of life are important for the child's mental and physical well-being.

3. Family Health

Programs to prevent mental retardation due to pre-natal, peri-natal and post-natal factors are:

(a) Pre-natal Period: Counsellors should promote adequate nutrition for women before and during pregnancy; they should advise on prudent timing of pregnancies and on health maintenance, infection control, toxemia aversion and problems that might occur at delivery.

(b) Peri-natal Period: A trained person should always conduct the delivery and expert care should be available in the case of complications like premature birth or neonatal hyperbilirubemia.

(c) Post-natal Period: Attention should be given to the quality of mothering, to the prevention and control of infections, and to nutrition.

4. Infections

Many cases of mental retardation are caused by infections: tuberculous meningitis, measles, encephalitis, and intra-uterine rubella. All can be prevented by immunization.

Program

Maine does not have a state-wide coordinated program to prevent mental retardation. After a review of the programs of several other states, I recommend that Maine establish a program patterned on that of Tennessee, which established a "Governor's Task Force on Mental Retardation" in 1980. Surveying the incidence of various causes of mental retardation in Tennessee, this Task Force made the startling prediction that "By the year 2000, the incidence of mental retardation can be reduced by half. This will not happen unless a well-planned program of prevention is aggressively pursued."

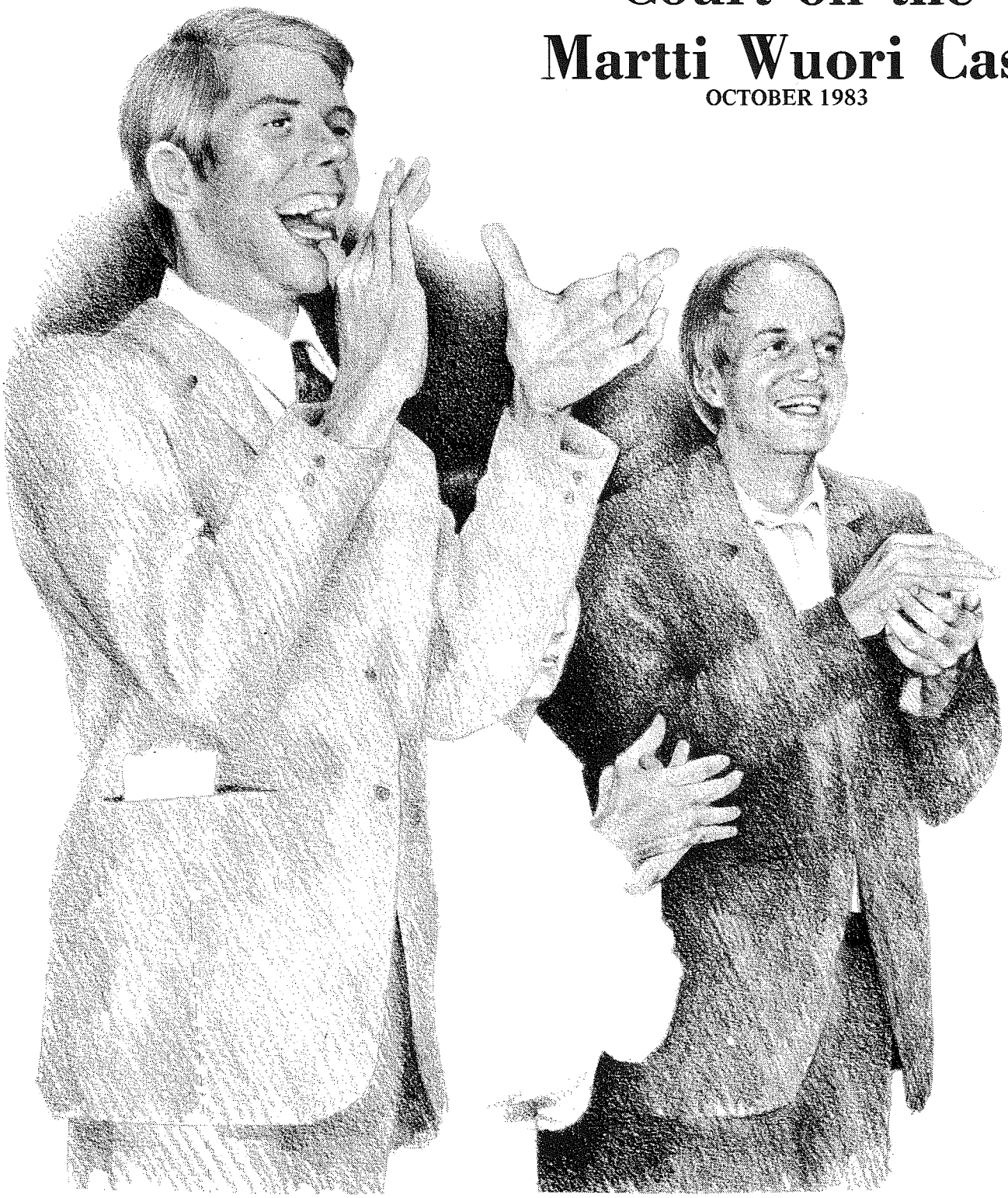
As the Special Master I submit that it would be prudent and wise for Maine to establish a State level "Blue-Ribbon" Task Force to identify, examine, and review the numerous initiatives currently underway that are aimed at prevention of mental retardation or early intervention. Needed additional prevention efforts should be recommended. Improved coordination and linkage to physicians and health educators would undoubtedly be a major focus of the Task Force.

Recommendations for legislation and funding could also be expected.

Steps to launch the Task Force should and need not be delayed. The Special Master was pleased to learn that the Developmental Disabilities council shares his interest in promoting a prevention program and is expected to come up with recommendations soon.

# Report to the Court on the Martti Wuori Case

OCTOBER 1983



## "All Systems Are Go!"

United States District Court
Portland, Maine 04112

LINCOLN CLARK
SPECIAL MASTER



October 26, 1983

The Honorable Edward T. Gignoux
United States District Court
Portland, Maine 04102

Re: MARTTI WUORI, et al., Plaintiffs
v.
KEVIN CONCANNON, et al., Defendants

Dear Judge Gignoux:

The attached report summarizes the actions taken by the defendants relating to the Consent Decree of July 14, 1978 concluding with the finding that they are in compliance and with a recommendation that the Office of the Special Master be terminated and that the defendants be discharged from the supervision of the Court. The concurrence of the parties is signified by their signatures at the end of this letter.

It gives me great satisfaction to submit this final report. I am especially proud that Maine is the first state to be found in compliance with a comprehensive Federal Court Decree aimed at improving the welfare of the mentally retarded.

Compliance does not mean that all class members currently receive every amenity and service stipulated in the Decree. It means that "all systems are go", and that nothing in the State's system of care and services impedes full realization of decreed rights to each plaintiff. The Decree is a "living document"; and its mandate will continually evolve and new concepts will emerge for the care and development of the mentally retarded. Following the termination of the Court's active involvement in this case the standards established by the Decree will continue to define the minimum level of services to be provided by the State.

Compliance is due to the remarkable, warm cooperation of the Legislature, many state and private agencies and individuals, and especially because of the persistence of the staffs of the Department of Mental Health and Mental Retardation and the conscientiousness of the plaintiffs.

The key to this cooperation stems from the Court's intimate involvement in working out with the Parties a detailed "Consent Decree" and the methods for assuring ultimate compliance with it. Maine now has an excellent system of care for its mentally retarded citizens and I am confident that it will become even better in the years ahead.

William D. Kaufman
Attorney for Defendants

Attorney for Plaintiffs

Attorney for Plaintiffs

Respectfully submitted,

Lincoln Clark

Lincoln Clark, Special Master

t

TABLE OF CONTENTS


| | | Page |
|---|---|---|
| 1. | The Consent Decree | 1 |
| 2. | Plans of Correction | 11 |
| 3. | Audit of the Consent Decree, Appendix B | 12 |
| 4. | Pineland Center | 15 |
| 5. | Post-Decree Implementation | 16 |
| 6. | The Consumer Advisory Board | 17 |
| 7. | The Medicaid Waiver | 18 |
| 8. | Hospital and Nursing Home Employment Programs | 19 |
| 9. | ShelterCraft | 22 |
| 10. | Prevention of Mental Retardation | 23 |
| 11. | The Future | 24 |


EXHIBITS


| | | |
|---|---|---|
| A. | "Audit of Compliance of Stipulation Agreement Plans of Correction Numbers 9, 12 and 13" by Dr. Alex Pattakos | E-1 |
| B. | "Living in Maine: An Audit of the Consent Decree, Appendix B" by Professor Sally M. Healey | E-21 |
| C. | Report of Superintendent of Pineland Center | E-51 |
| D. | Auditing of Decree Standards | E-53 |
| E. | Role of the Consumer Advisory Board | E-56 |
| F. | Waiver Committee | E-58 |
| G. | "Nursing Home Industry" by Michael McNeil | E-60 |
| H. | "Planning Project for a Statewide Program for the Prevention of Developmental Disabilities/Mental Retardation" by Medical Care Development, Inc. | E-81 |

## 1. The Consent Decree

In 1975 a lawsuit was filed on behalf of Martti Wuori and other residents of Pineland Center contending that the State did not have an adequate system for the care and training of mentally retarded persons at Pineland Center and in the community. Pineland Center was overcrowded despite the discharge of over a thousand residents during the previous twenty years. Many of these who had been discharged were receiving little or no follow-along service or were lodged in large old boarding homes which did not provide adequate habilitation services. The facilities at Pineland Center as well as at many boarding homes needed improvements. Training and professional services were insufficient both at Pineland Center and in the community.

These issues were dealt with in protracted negotiations culminating in 1978 in a "Consent Decree" composed of two parts, Appendix A relating to Pineland Center, and Appendix B relating to the community.

In order to implement the Consent Decree which emphasized the placement of Pineland residents in community facilities and the provision of better services in the community, the "Intermediate Care Facilities/Mentally Retarded (ICF/MR)" program was instituted. This program, cooperatively financed by the Federal and State governments, enabled a significant number of Pineland residents to be served adequately in the community and at Pineland Center.

At the expiration in 1980 of a two-year period during which it had been hoped that Decree standards would have been reached, there were still some problems. Over half of the Pineland residents scheduled for community

placement still had no suitable place to go in the community, and many clients were still in over-large, programmatically unacceptable homes, without the active day program services required for them to progress according to their individual capacities. Fortunately, a "Stipulation Agreement" was reached, which served to avoid protracted litigation. The Stipulation Agreement noted deficiencies in the system and set forth fifteen "Plans of Correction" with timetables for their accomplishment. Section 2 of this report contains summaries of the achievements under each Plan. The full reports on the Plans have been separately submitted to the Court.

Upon assuming the Office of Special Master in 1981, I made a quick survey of the problems to be resolved in order to achieve compliance with the Decree. Finding that Pineland Center had significantly improved, I decided to give top priority to its few remaining deficiencies and to ways of assuring continuing compliance with the Decree standards after their achievement. On September 18, 1981, the Court found Pineland Center to be in compliance and transferred from the Office of the Special Master to the Bureau of Mental Retardation the responsibility for maintenance of the standards in the Decree. This action by the Court was not only a tribute to the staff of Pineland Center but spurred all workers in the State system to reach compliance with the community part of the Decree.

The Parties met at least monthly to evaluate progress on the fifteen Plans of Correction, finally concurring on July 12, 1983, that all Plans had been met. The Parties also agreed on procedures for post-decree auditing and monitoring. That left one major issue: how to assure the financing

of about 300 more placements and services in the community for persons who have been in inadequate community residences and the financing of an additional 180 Pineland Center residents. I have delayed issuing this report until this issue was resolved by Federal approval of the Medicaid Waiver, which is discussed in Section 7.

2. Plans of Correction

In order to deal with deficiencies in the community mental retardation system, the Parties reached a Stipulation Agreement on January 14, 1981, in which the Defendants agreed to develop fifteen "Plans of Correction," to serve as blueprints for action and as measuring sticks of compliance with Appendix B of the Consent Decree.

The progress of the fifteen Plans has been reviewed in monthly meetings of the Parties with the Special Master concluding on July 12, 1983, when all the Plans were deemed to be in compliance. Summaries follow, concluding for each Plan with the date of the Special Master's final report of compliance.

Plan of Correction No. 1: All clients shall be removed from Seven Elms Boarding Home, Willowcrest Boarding Home and Hilltop Boarding Home.

Seven Elms Boarding Home -- All clients have been removed. Willowcrest Boarding Home -- All but two clients have been removed. The two who remain are doing so with the concurrence of the Interdisciplinary Team. Hilltop Boarding Home -- All but one client has been removed. That one is remaining because of family preference. (July 30, 1982)

Plan of Correction No. 2: After an evaluation of the residential and program services at Ward's Home, Pinkham's Home (Strong Children's Home), and Northland Manor, all clients shall be removed or offered suitable programs.

The determination of the Special Master and the Parties that all of the homes except Strong Children's Home are in compliance was reported in the

July 30, 1982, report. Since then Strong Children's Home has been re-audited and found to be in compliance. The cottage renovations have been completed, programming is in place for each client, and a community integration program has been established.

Possibly the most challenging problem at Strong Children's Home was the community integration program, since most of the residents are profoundly retarded and physically impaired. The resolution included preparing a list, drawn from the "Community Integration Manual," of activities appropriate for each resident, providing for each resident to be taken into the community at least twice a week for activities, providing staff training on community integration, and documenting in a log the date and activity of each resident. (February 15, 1983)

Plan of Correction No. 3: The population shall either be reduced or the level of programming for clients shall be increased at the under-listed homes: Bruce Haven, Hall-Dale Manor, Tissue's Boarding Home, Noyes Boarding Home and Houlton Residential Center.

Bruce Haven -- One class member remains. Legal guardians have waived BMR services. Hall-Dale Manor -- There is a signed agreement to improve programming; off-site programming and in-home programming are available. Tissue's Boarding Home -- Two class members remain. The guardian of one has waived BMR services and the guardian of the other is considering alternate placement or waiving services. Noyes Boarding Home -- Record keeping needs improvement. Houlton Residential Center -- There is a signed agreement to improve services. Off-site programming is available. Inservice training documented. While the physical layout is not optimal, steps have been taken to make the facility more attractive. More attention should be given to the clients' rooms. Client records are very complete. (July 30, 1982)

Plan of Correction No. 4: A case review will be conducted for all clients in nursing homes that serve predominantly non-mentally retarded individuals. Upon completion of the case review, clients recommended for replacement shall be moved. Clients not recommended for replacement shall be reviewed by an on-site professional team for purposes of recommendations to upgrade programming.

The Parties and Special Master concurred with the auditor's finding:

"The Bureau carried out the individual case review, compiled a list of clients recommended for movement, developed regional plans to meet client needs, and moved clients within the provisions of Appendix B. Concerns arise when, due to the lack of alternative placement sites, interim plans for those not yet moved are evaluated. Many of these nursing homes are inappropriate because of their size. In addition to their size, the activities staffs are oriented to the geriatric population and not to the mentally retarded population. This leads in many cases to activities designed for the elderly being substituted for programming appropriate for a mentally retarded individual. It was not uncommon in the auditor's experience to hear a nursing home staff person say that the client does everything our other clients do. There also seems to be a reluctance by nursing home staff to request inservice training from BMR. The auditor recognizes the difficulty BMR has finding appropriate placements and encouraging ICF/MR-nursing development. However, with a few exceptions such as Oceanview, the auditor would discourage reliance upon the nursing home placement as an ongoing alternative, the auditor makes the following recommendations: (1) Utilize nursing homes when age appropriate and the client has

voluntarily resigned from off- and/or on-site programming. (2) When programming is an IDT recommendation, only those homes with access to off-site programming whould be considered. (3) When the only programming appropriate is on-site programming, the hiring of a one-to-one social service worker should be part of the IDT recommendation. (4) The BMR could be much more assertive regarding the appropriate inservice training for nursing home staffs. Initial or continued placement could be made conditional upon completed inservice training by nursing home staff. (5) The urgency for additional community placements should be reduced until existing needs have been met." (July 30, 1982)

Plan of Correction No. 5: After a case record review, the Prescriptive Program Planning Process shall be re-examined, and when necessary, restructured. A consultant has been employed to undertake the review and make recommendations.

This has been done. (July 30, 1982, and February 15, 1983)

Plan of Correction No. 6: The impact of the revised Prescriptive Program Planning process shall be statistically evaluated and further revised in accordance with the evaluation.

A report on this Plan was submitted in October 1982. It resulted in the Parties and the Special Master concurring that compliance with Plan of Correction No. 6 has been achieved. With the accomplishment of Plans No. 5 and 6, Maine now has a mechanism for assessing and planning to meet the needs of each individual client. (February 15, 1983)

Plan of Correction No. 7: The BMR shall assist the Consumer Advisory Board in making trained correspondents available for participation in the IDT meetings of all clients who are not able to advocate on their own behalf.

After conference with the Parties, it became clear that technical compliance of Plan of Correction No. 7 had been achieved. Because they agreed that the deficiencies noted in the auditor's report should be dealt with, the BMR, with input from the Consumer Advisory Board, has drafted and submitted to the Special Master an acceptable program. (July 30, 1982)

Plan of Correction No. 8: This Plan stipulates that the Defendants shall retain a consultant in vocational programming to evaluate, relative to Decree compliance, the programs of: Bangor Regional Rehabilitation Center (now Phoenix), Goodwill, Coastal Workshop, Pathways, Winthrop Work Activity Center and Green Valley, and thereafter formulate plans to bring these programs into compliance with the Decree.

An "Addendum to the State-Wide Plan' submitted in August, 1982, removed the previous concerns about implementation of this Plan. The Parties and the Special Master have concurred that this Addendum justifies a determination that compliance with Plan of Correction No. 8 has been reached. (February 15, 1982)

Plan of Correction No. 9: Defendants shall develop an instrument to identify unmet residential and programmatic client needs, by type and location. This instrument shall be utilized to determine and aggregate these needs, and to develop a plan for resource realignment or development where necessary.

The Plan contemplated under this Agreement has been in the course of development throughout this Special Master's tenure. It is clearly the most

critical of the plans, in that it establishes a procedure to achieve the Decree's overriding purpose of assuring meaningful community living and appropriate programming for the Decree's beneficiaries. It also provides the means for developing the community resources that Pineland residents will require in order to receive the placements they have long deserved (see Plan of Correction No. 15).

The needs of clients throughout the State were assessed in April, 1981, and twice since then. The Management Information System is in operation (see Plan of Correction No. 12). The Defendants are proceeding to take advantage of opportunities to develop appropriate residential and program resources, but clearly much more needs to be done. (July 12, 1983)

This plan was audited by Dr. Alex Pattakos. (See comments after Plan of Correction No. 13.)

Plan of Correction No. 10: A plan shall be formulated by designated representatives of the disciplines of psychology, occupational therapy, physical therapy, and speech therapy to recruit, develop and utilize professional resources to meet the needs of the Decree's class members.

A report to improve the means to attract and retain professionals was submitted in September, 1982, and resulted in the Parties and Special Master concurring that compliance has been achieved. (February 15, 1983)

Plan of Correction No. 11: Quarterly reports shall be made on problems and progress toward the alleviation of deficiencies in the following areas: transportation, crisis intervention, family support, respite services, and community recreational opportunity.

The quarterly reports have been made. The Parties and the Special Master

have agreed that an audit of this plan is not needed. Reports of the regional public relations coordinators will be incorporated in future quarterly reports. (July 30, 1982)

Plan of Correction No. 12: A plan shall be formulated to track clients' needs and for resource development.

The Defendants have developed and implemented a computerized management information system. (July 12, 1983) (See comments after Plan of Correction No. 13.)

Plan of Correction No. 13: A plan shall be developed to improve monitoring systems of services delivered to clients, to assure the quality of the services and to provide for prompt identification and correction of the deficiencies.

The implementation of Plans of Correction Nos. 9, 12, and 13 was audited by Dr. Alex Pattakos, Director, Applied Research and Consultation Services, Bureau of Public Administration, University of Maine at Orono.

Dr. Pattakos concludes that the Defendants have demonstrated a sincere commitment toward full compliance; they have developed "systems" to identify and track client needs, to plan for resource development, and to monitor that the services delivered to class members are on the "right" track. Dr. Pattakos also offers many recommendations for improvement of the "systems." His report is summarized in Exhibit A.

At a meeting with Dr. Pattakos on July 12, 1983, the Parties and the Special Master accepted his report and concurred that the Defendants are in compliance with Plans of Correction Nos. 9, 12, and 13.

Plan of Correction No. 14: A plan shall be developed for training all employees and service providers to meet Decree standards and the purposes of the Plans of Correction.

The report of the auditor, Dr. Vernon Patterson, was reviewed in January, 1983. The Parties and the Special Master endorsed his report, which found that the Defendants are in compliance. (February 15, 1983)

Plan of Correction No. 15: Pineland Center shall re-establish its Planning Committee to ascertain the best suited community placement for each current resident and transmit its finding to the BMR for incorporation in a long-term community development plan.

This plan has been developed by the Defendants and is being incorporated into the BMR's State-wide development plan, as required by Plan of Correction No. 9. The Parties and the Special Master have concurred that compliance has been achieved. (July 30, 1982)

3. An Audit of the Consent Decree, Appendix B

The fifteen Plans of Correction were essentially "inputs", that is, what the State should do to achieve the standards set forth in Appendix B of the Consent Decree. In order to check whether the input has in fact produced the output of improving the lives of the class members as called for by Appendix B, Professor Sally M. Healey, Human Services Programs, Bangor Community College, University of Maine at Orono, was retained by the Office of the Special Master for a special audit. A summary of her report is Exhibit B.

At a meeting on June 29, 1983, the Parties and the Special Master concurred with the auditor's finding that the Defendants are in compliance with the provisions of Appendix B.

The following recommendations are not reservations regarding the preceeding finding but are simply suggestions of the auditor for further improvement.

1. Procedures used to monitor the quality of services for class members are less structured and well-defined than they need to be. As more class members move back into the community it will become even more necessary to analyze the frequency, content, and documentation of home and agency visits. Obviously efficiency and cost-effectiveness are important; the channeling of resources into the direct-care services to which the monitoring is directed! The case managers' roles and functions should be more clearly defined so that homes and agencies will have more realistic and consistent expectations of what case managers can do. Input about the monitoring process should be solicited

from homes and agencies in order to maintain a productive partnership in the business of providing the best possible services for people with mental retardation.

2. Crisis intervention services should continue to emphasize prevention and to de-emphasize the use of state institutions. The development of proactive direct care staff is an important step in this direction. If the BMR staff had more empirical data about situations requiring crisis intervention services they could analyze variables contributing to or mitigating these crises and then perhaps learn to avoid some high-risk situations.

3. Inservice training regarding psychotropic medication, and especially its possible side effects, should be provided for all BMR case managers and their supervisors. Repeated reminders such as have given by Commissioner Concannon, to psychiatrists and physicians regarding Decree requirements for "drug holidays" may provide the impetus for the medical community to examine procedures in the use of psychotropic medication.

4. Methods to enhance social integration and to provide leisure time opportunities should continue to be examined. The statement by many of the class members interviewed that they have no friends with whom they visit is a sad one. Salzberg and Langford (1981) suggest some alternatives, including a companion or friendship model which originated in the Nashville-Davidson County area of Tennessee. This is certainly a difficult problem to address, but, given the creative and unique programs already established in Maine, it is not an insurmountable challenge!

5. The Individual Program Planning Process is an excellent one. Especially important is the ongoing self-evaluation built into the process. The general enthusiasm from direct care and case management staff regarding the process confirms its appropriateness. Class members have voiced some concerns regarding the meetings. Perhaps a short interview with each client right after his or her meeting would provide some "consumer" input to the self-evaluation. Adherence to the procedures set forth in the 1983 Individual Program Plan Manual would meet and even exceed the Standards set forth in Appendix B.

6. All staff working with people with mental retardation should be aware of their legal rights, in order to protect these rights and to function as advocates when necessary. The rights set forth in Chapter 186-A and Chapter 229 should be strongly emphasized through ongoing inservice training.

4. Pineland Center

The programs of Pineland Center both at the Center and in the community will continue to expand as residents transfer to community homes under the provisions of the Medicaid Waiver. A report of the Superintendent is Exhibit C.

5. Post-Decree Implementation

Since the standards in the Consent Decree remain in force indefinitely, the Court and the public want continuing oversight after the Office of the Special Master is terminated. The Parties and the Special Master have agreed on a plan for the annual "Auditing of Decree Standards" (See Exhibit D). Compliance with the standards will be checked by an audit of a third party or parties qualified to perform such an audit.

Since it is not deemed necessary to audit performance with respect to every standard every year, the plan provides for the public to make suggestions of topics that should be examined by the auditor and to receive a report on the auditor's findings and on the plans for corrective action to be taken by the Bureau of Mental Retardation.

6. Consumer Advisory Board

The Consent Decree provided for the establishment of the Consumer Advisory Board to review the practices of the Defendants from the point of view of the class members. This Board has been functioning since 1978, with special success in recruiting "correspondents" for class members all over the state. The correspondents have been so effective that the BMR plans to extend the system to all of its clients -- non-class as well as class members.

Upon termination of the Office of the Special Master, the responsibility of the Consumer Advisory Board will increase. In order to refine the "charge" of the CAB, the Parties and the Special Master, after consultation with Board members, agreed on the "Role of the Consumer Advisory Board" (See Exhibit E).

7. The Medicaid Waiver

The final element necessary to ensure continued compliance with the provisions of the Consent Decree was the successful implementation of the State's application to the Federal Health Care Finance Administration. The system set forth in the application, which was sponsored by the Departments of Human Services and Mental Health and Mental Retardation, will provide home and community based services to 400 mentally retarded persons who would otherwise be or remain institutionalized. Included are professional support services, respite care, transportation, day habilitation, and foster home and boarding home care. This so-called "Medicaid Waiver" will provide the programmatic and financial resources for community placement of Pineland residents and will prevent unnecessary institutionalization of persons already living in the community. Staff of the Departments of Human Services and Mental Health and Mental Retardation are completing the administrative framework of this program so that services may begin immediately upon Federal approval.

Once funds are available for needed programs, it is important to assure that there are good plans for utilizing the funds. Toward this end a Waiver Committee was appointed to assist the Special Master in determining the adequacy of the plans. This Committee has served well. The work of this Committee is summarized in a letter sent to Donald V. Carter, House Chairman, Appropriations and Financial Affairs (see Exhibit F), arranging with the Approriations Committee to include the following language in L.D. 1354, the Part II Budget:

> "The Departments of Human Services and Mental Health and Mental Retardation shall report to the Committee on Appropriations and Financial Affairs on a quarterly basis as to the status of the Medicaid Waiver Implementation Plan."

8. Hospital and Nursing Home Employment Programs

There are about thirty-five sheltered workshops in Maine offering programs for the development of their clients' working skills. These workshops are an essential element of the continuum of Maine's programs to develop the capacities of clients to the maximum. It is generally accepted that every effort should be made to have clients graduate from such programs to more "competitive" employment. Several sheltered workshops actively seek outside employment activities for their clients, but some are so busy with their primary day-to-day operational responsibilities that the goal of graduation is slighted. It takes lots of time and effort to place clients in outside jobs.

In order to supplement what the sheltered workshops are doing about job placements, several approaches have been considered. A major decision has been to focus on the health industry as one where employment of the developmentally disabled is especially promising. Not only do employees in the health industry generally have the compassion required to welcome mentally retarded workers but from a practical point of view the industry, with a very high labor turnover in a number of less skilled jobs, needs the steady, conscientious help that mentally retarded persons can give.

The hospital employment program began in 1982 at the Maine Medical Center in Portland, and has already been extended to the Webber Hospital in Biddeford and the Thayer Hospital in Waterville. It will soon be extended to other hospitals. The goal is twofold: (1) to offer training and services that focus upon an identifiable vocation or occupation, and to develop the specific skills to perform this vocation or occupation; and (2) to offer

opportunities to acquire appropriate skills so that individuals can work toward employment at the Maine Medical Center on a full-time basis and can if desired, transfer to other areas of the hospital or to outside facilities.

The program at the Maine Medical Center began with twenty disabled persons working in the dishwashing and service area and in the assembly line of the food services department. Then some persons were assigned to work in the laundry department and others to wrap up sterilized surgical instruments. Additional kinds of activities are being evaluated. The quality of the disabled persons work has been excellent, their productivity has been steadily increasing, and their attendance has been exceptional. A factor affecting the increasing productivity is that many are now, for the first time in their lives, in direct competition with non-retarded persons and they want to keep up! "They don't drop as much silverware down the garbage disposal as our regular employees." The Food Services Department and the Maine Medical Center have actually seen a financial savings because of this program. The turnover rate, traditionally high in this department, has been reduced substantially, resulting in reduced need for advertising, interviewing, orientation, and overtime. The disabled individuals are members of the team of the Maine Medical Center. They receive a M.M.C. check, they are eligible for M.M.C. benefits. They become members, with I.D. numbers, of the Maine Medical Center family. They are not identified with a "Sheltered Workshop," but rather with the M.M.C. and its other 3,000 employees. The impact on the self-image of these employees is significant. Because of past experiences these retarded individuals never dreamed of holding a full-time job with full benefits, without the "stigma" of being labeled retarded. They

are productive citizens now, and paying their way! The dedicated staff of the program, as well as the leadership provided by the Maine Medical Center, should be applauded.

The Maine Medical Center program has gained national recognition. On August 13, 1983, at the National Rehabilitation Association's Conference in Boston, M.M.C.'s "Hospital Industries" Program received the 1983 Organizational Award. In addition, the U.S. Department of Health and Human Services has granted $120,000 to the Maine Medical Center to develop similar programs in five other hospitals in Maine, New Hampshire and Massachusetts.

The success of the hospital employment program has led to an exploration of its extension to nursing homes. Michael McNeil of Berry, Dunn & McNeil sampled 140 nursing homes in Maine. His report is Exhibit G. Its conclusion is that there is a significant employment potential in the nursing home industry and contains several recommendations and that there is an important connection between the hospital and nursing home programs. Hospitals may serve as the initial "training centers." Graduates will go to work in nursing homes, but, later on, a training center may be established in a nursing home.

9. ShelterCraft, Inc.

There are about 750 clients in 35 work activity centers and sheltered workshops in Maine. Some workshops have highly developed programs to produce and sell industrial products such as pallets, potato barrels, fish storage boxes. Some have quite large-scale subcontracts to assemble parts of products for industrial companies. Others make a wide variety of wood and textile gift items, toys and household products. Making these products develops work habits and skills and increases the income of clients.

Because of their remoteness from markets and their lack of resources, some of the workshops have not been able to expand the markets for their products. Some need technical assistance on product design, packaging and pricing. In order to help, ShelterCraft, Inc. has been established with a start-up grant from the Bureau of Mental Retardation and the Bureau of Vocational Rehabilitation. The aim of ShelterCraft is to be self-supporting within a year or two. A temporary manager is now hard at work developing a plan of operation.

The first public showing at the "Merchant's Place" at the Howard Johnson Motel in Portland, October 1 and 2, presented sixty-six products.

10. Prevention of Mental Retardation

Previous reports of the Office of the Special Master have dealt with the importance of prevention. It is gratifying to report that significant progress is underway.

In order to develop an agenda for a prospective task force, the Bureau of Mental Retardation secured the services of the Medical Care Development, Inc. of Augusta. M.C.D. has prepared a monumental draft report surveying the developmental disabilities programs in Maine and other states and offering twenty-five recommendations. The Developmental Disabilities Council is currently reviewing this report and is expected to complete a working document in October. Of this report, two sections have been repooduced in Exhibit H.

The conclusion of the Martti-Wuori Case is a great accomplishment. An even more significant legacy for Maine would be the implementation of a coordinated prevention program.

## 11. The Future

The conclusion of the Martti Wuori case is a fine accomplishment. It has greatly improved the system of housing, care, and development of Maine's mentally retarded citizens. This has been the focus of effort of hundreds of people for at least eight years. Now the State's camera needs a wider-angled lense. Its focus should be broadened to include two major needs that are not covered by the Consent Decree. One is a vigorous program to prevent mental retardation so as to reduce the number of entrants into the system; the other is to graduate more of the system's clients into employment in the community. The savings will be great -- less grief for parents, less burden on taxpayers, and more joy for clients.

EXHIBIT A: Audit of Compliance with Plans of Correction Nos. 9, 12 and 13

by

Alex N. Pattakos, Director
Applied Research and Consultation Services
Bureau of Public Administration
University of Maine at Orono
Orono, Maine 04469

June 1983

The charge to the auditor was to assess, from a systemic perspective, the defendants' capacity to achieve full compliance with Plans of Correction Nos. 9, 12, and 13. Although this audit was not explicitly client-focused, it did by design relate to client concerns, primarily through a complementary client-specific audit which, in large part, addressed the same items. Moreover, it should be noted that the charge to the system auditor was restricted to the BMR. The review did not directly involve other parties concerned about Maine's mentally retarded citizens, such as non-BMR service providers, funders, advocates, etc.

## PROCEDURES

In terms of methodology, this audit report can best be described as a qualitative analysis. Although qualitative evaluation efforts often appear to lack the precision of quantitative studies, this is not always the case. Moreover, there are sound, rigorous, and acceptable methods for conducting qualitative evaluation studies (Patton, 1980).

The findings and conclusions reported in the following sections were obtained from both primary and secondary information sources. The auditor collected qualitative data through direct observation of selected activities, such as an MIS staff training session. In addition, personal and/or telephone interviews with a purposeful sample of participants for each Plan were conducted. Selected BMR staff also responded to a number of requests for particular information.

A wide variety of secondary information sources was examined. Such materials included pertinent documentation of BMR's compliance activities

for each Plan, such as resource development plan forms and summaries (#9), MIS user instructions and reports (#12), and various planning and monitoring reports and memoranda (#13). Moreover, the auditor reviewed all Reports to the Court by the Special Master, relevant external consultant/auditor reports (such as those by BLF, Inc. and Dr. Robert Audette), selected internal reviews conducted by BMR, and pertinent BMR program policy statements. A sample of client case records was also examined. Particular attention was devoted to reviewing the defendants' IPP process.

For comparative purposes, efforts were made to obtain the most current "state-of-the-art" information from other jurisdictions, organizations, and publications in the U. S. regarding the major issues addressed in this audit. A comprehensive search of Project SHARE's data base, a national clearinghouse for improving the management of human services operated by the U. S. Department of Health and Human Services, was conducted in two key areas of concern -- client monitoring/tracking systems and management information systems. Communication links were established with persons knowledgeable about similar class action suits in other states. In addition to information obtained directly from the Special Master in Pennsylvania, the reports of an external analysis of the Pennhurst case, conducted by Human Services Research Institute, Boston, Massachusetts, were also examined. Likewise, a review of pertinent literature in the public management field, with emphasis on contemporary human services administration practice, was conducted.

Finally, the results of the complementary client survey audit were analyzed and integrated into the findings and conclusion contained in this

report. Since the systems auditor was involved in the sampling design and data processing phases of the client survey audit, he was able to examine the relative compatibility of the client survey results with the broader, systemic concerns of this review.

FINDINGS

The evidence clearly illustrates that the defendants have pursued an "evolutionary" course of capacity development in all areas covered under Stipulation Items Nos. 9, 12, and 13. While the BMR's capacity, in particular, has not developed at the same rate in all areas of concern, the trend lines are not that difficult to discern and, in the auditor's opinion, aptly demonstrate a predisposition towards change and system improvement.

Moreover, the auditor, for the most part, witnessed a partnership (as opposed to an adversarial) approach to resolving the issues imposed by the Consent Decree among the parties involved. While at first glance this may not appear to be terribly significant, this atmosphere is relatively unique among jurisdictions facing similar challenges in the human services, including community mental retardation services, arena. Indeed, more typically, an organizational pathology known as the "territorial imperative" (Berkley, 1981, pp. 92-95) controls and thereby inhibits the actions of similarly-situated parties, sometimes to such an extent that the state's response to litigation becomes merely another organizational game rather than an opportunity for service system development. Interestingly, the spirit of cooperation which prevails in Maine with regard to the Pineland Center case has even received national attention (Bradley, et al., 1982).

Of course, to say that there is a cooperative spirit among the parties in Maine does not necessarily mean that interorganizational and inter-jurisdictional problems do not exist. The BMR's overall accomplishments to date have directly influenced its relations with other, presumably allied, state and local agencies in various and not always complementary ways. Clearly, the State's mental retardation system has developed rather quickly requiring accommodations from without as well as within its not easily-defined boundaries. Recent legislative and executive initiatives, which highlight the concern about organizational interfaces between the BMR and other state and local agencies, provide testimony supporting such a contention. Although this dimension of the defendants' capacity was not an explicit focus of this review, it still is an important issue which will warrant careful attention in the future.

IPP Process

Unquestionably, the IPP process is the critical linchpin which holds all of the "systems of compliance" together. This process has passed through a number of evolutionary steps since its inception in 1977. It is a viable process, one which seems to have considerable support among both management and service delivery personnel. The data from the client survey corroborate this point. The evidence suggests that the IPP does reflect actual client needs. Put differently, there is no real evidence that the IPP does not reflect actual needs. This observation, of course, is in marked contrast to some of the earlier criticisms directed at the IPP process.[1]

---

[1] See Office of Special Master, Report to the Court, "Community Standards: Appendix B of the Court's Decree," April 22, 1980, as well as the Stipulation Agreement of January 14, 1981.

Conceptually, the purpose of the Interdisciplinary Team (IDT) and, in particular, its end-product, the Individual Program Plan (IPP), is sound. In actuality, the underlying philosophy of the BMR's IDT/IPP format reflects contemporary human services ideology which purports to view clients holistically, that is, focusing on clients as complex individuals, and planning service responses which address the totality of individual and/or family needs (Agranoff and Pattakos, 1979, particulary pp. 13-39). The evolutionary development of the IPP process is well documented by the BMR, including a series of program policy statements, written reports of external and in-house reviews, and a newly (as of this writing) revised edition of the Individual Program Plan Manual. The Manual does an excellent job of describing the entire IPP process, in order to facilitate IDT member preparation and participation and thereby enhance its utility as a diagnostic tool for both planning and evaluation purposes.

Examination of the IDT/IPP process pointed to several areas of concern which relate to the compliance issues addressed in this report. First, it is promising to note that IDT participants, particularly service providers, seem to be more inclined to focus on measurable goals and objectives when formulating IPPs. While this trend is admittedly a positive one, the emphasis on client developmental goals, as well as the identification of alternative living arrangements, may become even more important in the years ahead. The pressure to deinstitutionalize typically decreases as more and more clients are moved out of traditional institutions into various community living arrangements. Yet, because nontraditional institutions, such as boarding homes,

may be similarly restrictive of individual rights, etc., as their more traditional counterparts (Lerman, 1981), the notion of least restrictive setting is no less significant within community settings. There will always be concern that the goal of deinstitutionalization will not necessarily result in the least restrictive setting for the clients. Therefore, more rather than less attention to this concern via the IDT/IPP process may be called for in the future. Overall, the prognosis in the State of Maine regarding the IDT/IPP process is clearly optimistic, due to the various refinements (in attitude, knowledge base, and behavior). Indeed, it is to the defendants' credit that such substantial improvements in this key area have been realized in such a short time frame.

Moreover, the IPP process is being used more frequently with nonclass members -- perhaps a promising trend if one considers nonclass members to be prospective class members.

Future enhancements of the IPP process will largely depend, of course, on ongoing monitoring of its use. The auditor therefore supports the idea of a peer review of the IPP process at regular time intervals. In order to provide feedback more frequently, perhaps a small random sample of clients should be selected for review with a more narrow array of IDT/IPP elements to be examined than what was done previously. Moreover, the IPP review forms should incorporate a service obstacles section for identification and discussion purposes. The explicit formatting of such information may make it easier to identify potential bottlenecks in the service delivery process, as well as gauge how well the IPP process deals with such issues.

Information Management

With regard to Stipulation Items Nos. 9 and 12, the defendants have firmly established the elements of a comprehensive information system to complie client needs data for resource development and related program planning purposes.

It is important to underscore the relationship between the activities conducted pursuant to Item #9 and those which culminated in the Management Information System (MIS) under #12. The identification of unmet residential and programmatic client needs, including the statewide and regional resource development plans which were formulated therefrom, was the cornerstone of the BMR's manual and automated information management efforts. Data elements which were eventually used as the basis of the Audett Report,[1] were grounded in the evolving IPP process and reflected earlier developmental efforts of several BMR regional staff persons. Indeed, the formatting of the requisite data under Items Nos. 9 and 12 underwent several iterations since 1980.

The Audette Report served several purposes besides providing an inventory of unmet needs. It elicited favorable reactions in the BMR regions, even, on occasion, prompted revised needs data estimates, and brought to the forefront a number of substantive and methodological issues. For instance, discussions regarding definitions and use of key terms, as well as potential errors in FORM* completion, were evident. Even the articulation of policy positions, such as an interesting argument against a replacement strategy

---

[1]Robert H. Audette, "Planning the Community System for Mentally Retarded Persons in the State of Maine", October 2, 1981.

*Utilized as the primary data collection instrument in 1981, it became the precursor of subsequent MIS data input formats.

with respect to foster and boarding homes, crystallized as a result of the Audette Report. This kind of exchange is, indeed, significant for it highlights the dynamic nature of MIS development (Rosenthal, 1982). Moreover, it demonstrates that the BMR staff were not passive recepticles of expert consultant opinion regarding such critical questions. Instead, they were actively engaged, whether conscious or not, in the design and installation of whatever information management product emerged from this process.

Information supporting resource development planning, while based on needs data, such as those reported in the Audette Report and subsequently merged with the automated MIS (under #12), are arrayed manually in a variety of display formats. Although the resource development plan summaries presumably allow for comparisons of needed residential and programmatic resources with planned development of such resources, the auditor found it difficult to "separate the forest from the trees" and make this kind of basic comparison. The sample cover sheet in Exhibit I is proposed as one way of providing such a snapshot view, and could be done by region as well as statewide.

The formal MIS, which has been developed in response to Item #12, is grounded in the IPP process. The fact that, since 1979, the BMR has automated a greater portion of its information handling responsibilities should not imply that it has no shortcomings. Currently operating as a batch-mode system, its utility is naturally restricted, although not so much in terms of its program planning capacity. Its greatest weakness instead pertains to its use as an operational tool for case (client) specific

EXHIBIT I. SAMPLE RESOURCE DEVELOPMENT PLAN SUMMARY COVER SHEET

| Program/Residential/ Service Type | Need Estimates (date) | | | Development Plans (date) | | |
|---|---|---|---|---|---|---|
| | Community | Community Class | Pineland | Community | Community Class | Pineland |
| Fundamental Life | | | | | | |
| Practical Life | | | | | | |
| Personal, Social | | | | | | |
| . | | | | | | |
| . | | | | | | |
| . | | | | | | |
| . | | | | | | |
| . | | | | | | |
| Total Program | | | | | | |
| Independent Living | | | | | | |
| Semi-Independent Living | | | | | | |
| Supervised Living | | | | | | |
| . | | | | | | |
| . | | | | | | |
| . | | | | | | |
| . | | | | | | |
| . | | | | | | |
| Total Residential | | | | | | |
| Physician | | | | | | |
| Psychologist | | | | | | |
| Dental | | | | | | |
| . | | | | | | |
| . | | | | | | |
| . | | | | | | |
| . | | | | | | |
| . | | | | | | |
| Total Service | | | | | | |

tracking or monitoring. At this point, such monitoring is better handled manually by the BMR's cadre of professional client service coordinators (CSCs). Minus the installation of an on-line (i.e., conversational or interactive) system for case management decision-making, the likelihood that the current automated MIS will increase its usefulness among direct service delivery staff is relatively low. In the absence of information on associated costs and benefits of different MIS options, however, the practicality or feasibility of installing a more sophisticated system is uncertain. Since there are plans to upgrade the BMR's capacity in this area, such questions may be answered in the near future.

Whatever the outcome of the BMR's computer plans, it should be pointed out that the current system for case management is not unsatisfactory, by any means. This observation is based on the perceived attitudes and competence of BMR management and service delivery staff, as well as a quick look at similar systems in other jurisdictions. For the most part, the BMR staff have demonstrated an ethical commitment to service quality and deinstitutionalization which transcends purely legal obligations (Repp, 1978). In turn, this has fostered a spirit of cooperation rather than conflict among providers of services to the State's mentally retarded population. As mentioned earlier, this kind of atmosphere is somewhat unique among states which have had to comply with judicial decrees involving such value-laden, and potentially turbulent, issues.

The design, installation, and implementation of an MIS is, as indicated previously, a dynamic, ongoing process. It typically involves a series of

trade-off decisions which affect the extent, frequency, and level of detail of data collection and analysis, as well as the amount of system flexibility for the user. The successful implementation of a comprehensive MIS, like other human services innovations, particularly in decentralized service delivery networks, is dependent on several design criteria. Ideally, for example:

- the system must not increase the paperwork or reporting burden of line staff;
- the system must enrich and interface with already existing internal reporting systems;
- the system should support improved service delivery;
- the information generated by the system should flow into agency decision-making and the planning process.

In reality, of course, few, if any, systems satisfy the above criteria, and, no system can provide information for all conceivable decisions (Rosenthal, 1982). Managers responsible for different kinds of decisions, e.g., operating, planning, or evaluating, are likely to seek different qualities in an MIS, based on different information requirements. The acid test of an MIS is whether or not, given such requirements, it can process and prepare information in a usable format. At this level, it does not matter whether it does so manually or by computer, or, whether it processes data by "batch" or "on-line".

The BMR's MIS, broadly defined, needs to be examined with these conditions in mind. To reiterate, as a support for policy and program planning, the BMR's MIS does meet the utility test. On the other hand, within cost and other constraints, there are always refinements or adjustments in a MIS

which can be made to improve its usefulness. As a case in point, the auditor suggests the following regarding the automated portion of the BMR MIS:

1. That a client goals data base be added to the information on clients and service needs, in order to better target services to performance indicators, such as client development.

2. That the use of the Statistical Package for the Social Sciences (SPSS) be expanded and extended to achieve its fullest potential, i.e., more careful use of its labeling, data transformation, and subroutine capabilities, and highest degree of flexibility. Assuming that it will be used interactively, the BMR may want to consider its conversational option -- SCSS.

3. That the BMR FORM used for the MIS be redesigned as a pre-coded instrument (as much as possible) for immediate data entry and to decrease reliance/reference to codebook instructions.

4. That BMR staff training regarding the MIS include an orientation to system uses, processing opportunities and constraints, as well as expanded attention to definitions of key words and concepts.

5. That BMR reduce the workload associated with MIS data collection by:

   a. retaining its current level of information specificity with only a sample of clients; or,

   b. reducing the amount of information to only those items dealing with needs or problems, perhaps for a larger sample or total client caseload on a more frequent basis to flag issue areas needing further examination.

6. That BMR, in addition to developing its performance monitoring capability with the MIS, concentrate on preparing its MIS data for trend analysis, in order to depict change(s) over time as well as to enhance its forecasting capability.

7. That BMR establish a MIS users committee to provide input into system planning and operations, including technical assistance and training requirements.

8. That BMR coordinate its information management needs and resources with those of allied service agencies in an effort to reduce unnecessary duplication and overlap and to increase information scope and consistency/compatibility.

The above suggestions should not be construed as an indictment of the current status of the BMR's MIS. As indicated, the MIS data are being used for resource development, resource allocation, and other basic planning purposes. As a side benefit, moreover, management's emphasis on MIS within the BMR has underscored the importance of usable and used record-keeping throughout the agency.

Furthermore, the integrity of the MIS as designed has, to the auditor's knowledge, never been questioned by its users. Indeed, the presence of several cross-checks at different points in the data entry process has undoubtedly contributed to such integrity. In this regard, in addition to BMR caseworker and regional supervisor responsibilities, data accuracy is further assured by the DMH/MR Planning Division personnel who actually input and process the data. At all levels, the attitude towards the process is serious and strictly professional, leaving only a small margin for systematic, nonsampling error. The auditor's own review of various MIS data processing outputs also supported this relatively low error rate.

The perceived integrity of the MIS data, of course, is also substantiated by the many and varied uses for which the BMR staff have found it appropriate, such as legislative appropriations requests, supporting documentation for a Federal Medicaid waiver application, responding to requests for information from other state agencies, including joint planning activities. Continued efforts to mesh institutional and community information needs and resources into a coordinated, Statewide resource development/ monitoring support system provide further evidence of BMR's developing

capacity in this critical program management area. At least by implication such capacity-building intentions and activities increase the likelihood that the defendants will have in place those "engines of compliance" deemed essential to full compliance with the Consent Decree.

Montoring System

On balance, the defendants' response pursuant to Stipulation Item No. 13 follows very closely the evolutionary pattern described for Nos. 9 and 12. In this regard, major strides have been made by the BMR to assure the quality of services, direct as well as ancillary. The recent designation of a full-time staff person in the central office with quality assurance responsibilities manifests this commitment.

It is significant to note that a major portion of the BMR Quality Assurance Manager's responsibilities involves external relations with other state and community organizations. Because so much of what the BMR does with respect to its clientele is dependent upon the actions of others, the monitoring of interagency relations is clearly a key element of a viable monitoring system. Indeed, as former Special Master David Gregory has suggested, full implementation of the Consent Decree will not be assured unless the various responsible agencies cooperate with each other.[1] Yet, there is no reason to assume that interagency cooperation has any qualities of spontaneous growth or self-perpetuation (Reid, 1975, p. 128). As a consequence, facilitating effective interagency relationships typically constitutes a major expenditure item for human services organizations like the BMR, which is often the reason why interagency cooperation efforts fail.

---

[1]Office of the Special Master, "Report to the Court -- Continuing Supervision of the Decree," U. S. District Court, Portland, Maine, June 2, 1980, p. 11.

In this case, the BMR commitment to such a dimension of quality assurance should therefore be underscored. Already, for example, it has demonstrated that it can assume a key leadership role in assuring that the Inter-Agency Standards for Adult Community Programs are faithfully implemented. Moreover, the BMR's monitoring plan, which was submitted in partial response to Item #13, clearly substantiates itd dependency on, and need to work in collaboration with, other public agencies. Likewise, its implementation and monitoring procedures concerning residential services agreements further illustrates the direction of its monitoring responsibilities as required by Appendix B.

On another plane, the developing dialogue between central office, regional office, and institutional staff on service planning, case management, resource development, and case evaluation issues is another significant process indicator for at least predicting the direction, if not the magnitude, of the defendant's progress towards full compliance with Plan of Correction No. 13. A careful review by the auditor of central, regional, and institutional operational plans over several quarters revealed similar results. There is evidence, for instance, of not only increased use of the MIS for needs assessment and resource development planning as noted previously, but also closer integration of the institutions with community services development. Even acknowledging the variability across regions, the movement towards planning within a statewide context of goals and objectives promises to at least set the stage for a baseline planning and monitoring capacity for all parts of the BMR system. To be sure, the successful development of

any monitoring system is going to be an iterative process -- that is, one which is gradual and sensitive to bureaucratic and political realities. With this in mind, the BMR has come a long way with regard to its level of monitoring sophistication in only a relatively short period of time.

## CONCLUSIONS

On balance, the auditor finds the defendants to be in compliance with Item Nos. 9, 12, and 13 of the Stipulation Agreement of January 14, 1981. As described throughout this report, the defendants, in particular the BMR, have demonstrated, both in principle and in practice, a sincere commitment towards full compliance with these stipulated items. Evolving systems to identify and track client needs, to plan for resource development, and to monitor the services delivered to class members are on the right track. Moreover, these commitments and related actions are tangible evidence of the defendants' continuing efforts to achieve full compliance with Appendix B of the Consent Decree.

I would recommend that some external monitoring mechanism (or process) be established to review periodically the defendants' progress towards full compliance with Items 9, 12, and 13. The auditor did hear, of course, varied concerns about the potentially adverse implications of court withdrawal from its supervisory role. To a degree, the auditor shares this concern. However, the BMR's open system approach to managing its operations is, in my view, a significant counterweight to such threats. For example, the increased involvement and advocacy role of parents in the mental retardation services system is, at least partially, the result of BMR

initiatives. Over the long run, this kind of monitoring strategy may prove to have a more profound influence on service quality and outcomes than direct and continuous judicial oversight.

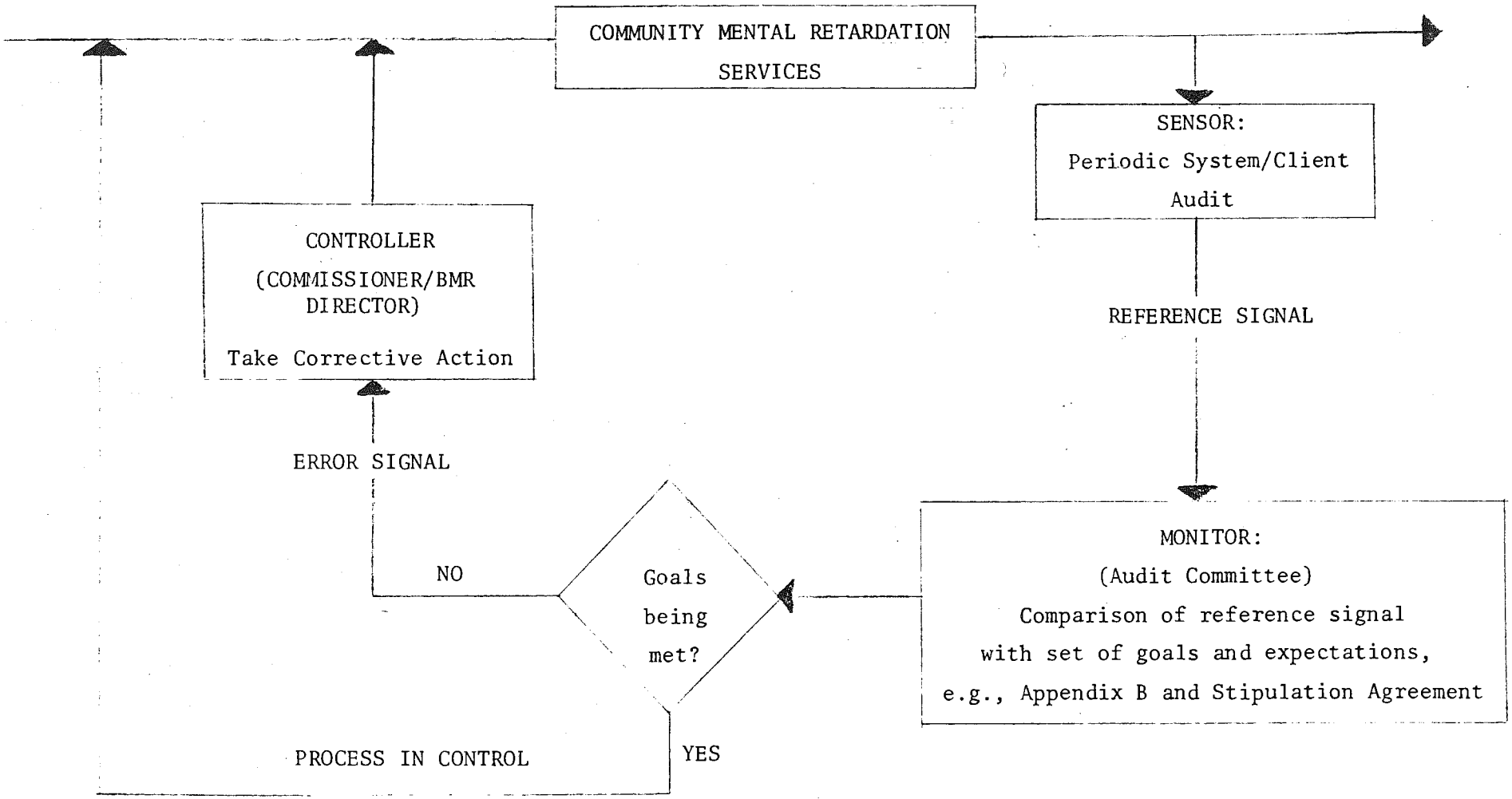
In the meantime, however, periodic reviews by some external, and officially-sanctioned, entity at reasonable intervals seems appropriate. Assuming, for example, that the waiver to allow the use of Medicaid Title XIX funds to pay for personal care services is granted, the need to independently review the defendants' behavior in some fashion may be even more important in the years ahead, in order to assure that resource development policies are faithfully implemented. Schematically, the basic elements of a monitoring (control) system are displayed in Figure 1. This diagram can easily accommodate the proposed process for "Auditing of Decree Standards" which has been already drafted by the parties. The monitor in the proposal is not identified, however. Rather, the proposed process links a sensor mechanism, e.g., public hearings and independent auditor, directly to the controller. Perhaps the Consumer Advisory Board, or something like it, should be considered as the "monitor" in this case.[1]

Finally, within the BMR itself, it is further recommended that the MIS data collection process be revised to reflect its planning rather than operational (i.e., direct service delivery) emphasis.* A semi-annual data collection effort would seem to be satisfactory for such purposes, unless, of course, the modified approach suggested earlier is adopted. In any event, in addition to the long-term view which is supported by such a (planning) information system, it is recommended that the BMR employ the spot-check, sample review of the IPP process, in order to continue to monitor and further refine its quality, both in terms of service planning and implementation.

---

[1] Office of Special Master, Report to the Court, "Community Standards: Appendix B of the Court's Decree," April 22, 1980, p. 20, wherein the Consumer Advisory Board is described as the "logical successor" to the Special Master.

FIGURE 1. SCHEMATIC DIAGRAM OF COMMUNITY MENTAL RETARDATION SERVICES CONTROL SYSTEM *




* Adapted from: M. Clinton Miller and Rebecca G. Knapp, Evaluating Quality of Care: Analytic Procedures - Monitoring Techniques (Germantown, Maryland: Aspen Systems Corporation, 1979), p. 96.

## REFERENCES


1. Agranoff, Robert and Alex Pattakos, Dimensions of Services Integration, Rockville, Maryland: Project SHARE Monograph Series, No. 13, 1979.

2. Berkley, George E., The Craft of Public Administration, Boston, Massachusetts: Allyn and Bacon, Inc., 1981.

3. Bradley, Valerie J., et al., Longitudinal Study of the Court-Ordered Deinstitutionalization of Pennhurst - Implementation Analysis: Department of Public Welfare, Boston, Massachusetts: Human Services Research Institute, Contract #130-81-0021, March 5, 1982.

4. Lerman, Paul, Deinstitutionalization: A Cross-Problem Analysis, Rockville, Maryland: National Institute of Mental Health, ADM-81-987, 1981.

5. Miller, M. Clinton and Rebecca G. Knapp, Evaluating Quality of Care: Analytic Procedures - Monitoring Techniques, Germantown, Maryland: Aspen Systems Corporation, 1979.

6. Patton, Michael, Qualitative Evaluation Methods, Beverly Hills, California: Sage Publications, 1980.

7. Reid, William J., "Interorganizational Coordination in Social Welfare: A Theoretical Approach to Analysis and Interaction," in Ralph Kramer and Harry Specht, eds., Readings in Community Organization Practice, Englewood Cliffs, New Jersey: Prentice-Hall, 1975.

8. Repp, Alan C., "On the Ethical Responsibilities of Institutions Providing Services for Mentally Retarded People," Mental Retardation, April 1978, pp. 153-156.

9. Rosenthal, Stephen R., Managing Government Operations, Glenview, Illinois: Scott, Foresman and Company, 1982.

EXHIBIT B: LIVING IN MAINE: A SUMMARY OF THE AUDIT OF THE MARTTI WUORI CONSENT DECREE, APPENDIX B

by

Sally M. Healey
Assistant Professor, Human Services Program
Bangor Community College
University of Maine at Orono

June 21, 1983

ACKNOWLEDGEMENTS

I would like to thank Alex N. Pattakos, Director, Applied Research and Consultation Services and Adrianne M. Comer, Research Aide of the Bureau of Public Administration, University of Maine at Orono for their many contributions to this audit. I would also like to thank the interviewers: Robert Keteyian; Margaret Quealley; and John Sommo; research assistant Robin Wortman; and typist Sandra L. Cayford. To the people who work in homes, day programs, Bureau of Mental Retardation regional offices, and to the families of the people we interviewed, I'd like to extend my appreciation for their openness and hospitality. And finally I'd like to thank the men and women who shared their lives with us.

## INTRODUCTION

This audit was requested by Dr. Lincoln Clark, Special Master of the United States District Court in the case of Martti Wuori, et. al. v. Concannon, et. al. Its purpose is to provide an independent evaluation of the lives of those class members who have left Pineland Center and are now living in the community, to determine whether or not the standards outlined in Appendix B of the Consent Decree are met in the actual, everyday lives of the class members.

In order to make this evaluation, an instrument was developed to measure the degree to which the standards have been met for individual class members. This instrument consisted of several interviews which were conducted with individuals significant in the lives of a representative sample of class members.

## METHODS

### A. Subjects

At the time of the audit there were 626 class members living in the community. In order to assess the quality of life for these class members at a particular point in time, a representative sample of this population was selected. This allowed for an in depth evaluation over a relatively short period of time. In order to make sure that each of the 626 class members had an equal chance of being selected for the sample, probability or random sampling of the population was employed. Random sampling ensures that human bias does not interfere with the selection of a group of subjects.

This group, or sample, can then be said to be representative of the population in question, in this case Bureau of Mental Retardation class member clients.

In order to minimize the sample size while still retaining a high degree of precision and confidence in the representativeness of the sample, a sample stratified by type of residence was chosen. Stratification is the grouping of an entire population according to particular characteristics which are, or are closely related to, one of the variables of interest in the study. By grouping the population by type of residence, it was possible to sample more of the subgroups in which there were larger members of individuals than the subgroups in which there were smaller members of individuals.For example, of the 626 class members, 106 people or 16.9% of the population were living in small boarding homes (3-6 residents) while four people or 0.6% of the population were in situations defined as "supervised living". Therefore the sample included more people living in small boarding homes than in "supervised living". The resulting sample of 52 individuals was drawn based on a 90% confidence level with a 10% margin of error.

Of the 52 class members selected for the sample 19 (36.5%) were women and 33 (63.5%) were men. One person was diagnosed as having normal intelligence, one person as having borderline mental retardation. Ten of the individuals surveyed had mile mental retardation, 17 had moderate mental retardation, 13 had severe mental retardation, 8 had profound mental retardation, and for two people level of mental retardation was not documented (these were people who had declined Bureau of Mental Retardation services).

Three of the class members surveyed were under 20 years old, 12 were between the ages of 21 and 30, 19 were between the ages of 31 and 40,

11 were between the ages of 41 and 60, and 6 people were 60 or older. Age was not available for one class member who had declined services.

Sixteen of the clients surveyed had no other handicapping conditions beyond mental retardation, 19 had one other handicapping condition, 13 had two other handicapping conditions and 4 had more than three other handicapping conditions. These data were not available for one class member.

B. Procedure

Instead of surveying only the class members themselves as has been done in other studies (Campbell, 1976: George, 1979; Lehman, 1982), those considered to have a significant impact on the life of each class member were also interviewed. These interviews were designed to elicit both objective data, for example daily schedules, as well as subjective data regarding the particular individual being studied, such as the direct care staff person's feelings about his/her relationship with the individual. In addition, interviews were conducted with class members and/or their parents or siblings when possible. Other information was obtained from each class member's Bureau of Mental Retardation case record.

The survey instrument consisted of four questionnaires which were administered as structured interviews. Separate questionnaires were developed for day program providers, residential care providers, case managers from the Bureau of Mental Retardation and clients and/or their families. Content of the questionnaires was based on the standards outlined in Appendix B (ommitted from this summary). Each of the questions was open-ended, that is, respondents were not given responses from which to choose.

A face sheet was also completed for each client. Variables such as age, sex, level of mental retardation, size of residential facility, number of roommates, number of residential placements since leaving Pineland Center and length of time in current home and program were included.

Interviews were conducted with direct care providers in residences and day programs, Client Services Coordinators employed by the Bureau of Mental Retardation and in some cases, clients and/or their parents or siblings. Providers interviewed in day programs and residences were those involved in at least some direct care with the client, were familiar with his/her schedule and programs, and had been employed by the home or program for at least six months.

Three interviewers, in addition to the author of this report, conducted the interviews. All attended two training and discussion sessions, one held prior to the interviewing and one held during the interviewing phase. During these sessions, each questionnaire was reviewed closely in order to maximize reliability across interviewers. At least weekly telephone contact with the author was maintained during the interviewing phase.

The interviewing phase began in December 1982 and concluded in March 1983. Interviews were conducted in homes, day programs and regional offices of the Bureau of Mental Retardation in all six geographic regions of the state. Interviewers also reviewed client case records and Individual Program Plans. They also wrote a narrative summary of each client's situation.

Data generated by the survey instrument was either numberically coded or compiled in narrative form. Since the purpose of this survey was to

provide a descriptive evaluation, the coded data was analyzed in terms of simple frequencies and percentages. The variable and value labels utilized in the processing of the coded data are in the Survey Code Book in Appendix 3 (omitted from this summary).

## RESULTS

Over half of the class members surveyed are living in homes with six people or less. Of the remaining individuals most live in homes with seven to 30 other residents while the smallest number of class members live in homes of over thirty residents. The larger homes tend to be Intermediate Care Facilities. One class member was living temporarily at Pineland Center at the time of the survey.

The majority of class members surveyed are living with one roommate or no roommates. The remaining individuals live with two or three roommates.

Most of the class members surveyed attend day programs outside their home. Individuals not attending outside day programs had either chosen not to attend an available program; were involved in an "in-house" day program for medical reasons; or were in emergency or respite placement at the time of the survey. There were no individuals for whom the Individual Program Plan had prescribed a day program who were not able to go because of the lack of an available day program.

Almost half of the class members surveyed have lived in their current home or one other home since leaving Pineland Center. Of the remaining individuals most have lived in three to six homes since leaving and only a few have lived in more than six homes.

One-third of the class members surveyed have lived in the community for ten years or more; one-third between five and ten years; the remaining third less than six months to five years.

Of the class members regarding whom a Bureau of Mental Retardation Client Services Coordinator was interviewed, most were felt to be in the least restrictive alternative. The most common one year projection made by CSC's for their clients was that they would be living in their current home. In making a five year projection, CSC's saw their clients most typically living in their current home, moving to an Adult Foster Home or to a Supervised Apartment, Group Home or Boarding Home. Very few CSC's saw their clients moving to Intermediate Care Facilities or living on their own. None saw state institutions in any of their clients' futures.

Of the class members surveyed approximately one-fourth have had to return to Pineland Center at least once since leaving. The most common reason for return is behavior problems; other reasons include medical or dental treatment; respite care or the lack of a day program.

Of the class members for whom CAC's felt behavior problems were keeping them in a more restrictive alternative or threatening their current placements, all had had psychiatric or psychological services.

CSC's for ten individuals related situations involving emergencies and subsequent crisis intervention services. Two were medical emergencies and were handled by community medical facilities. The remaining eight involved serious behavioral or legal problems such as: stealing; bizarre and disruptive behavior; threatening and aggressive behavior; and suicidal gestures. Of the eight incidents, five involved admission to either Bangor Mental Health

Institute, Augusta Mental Health Institute, or Pineland Center. In the other three cases community mental health centers, BMR workers, or an advocate provided crisis intervention services in the community.

When asked to assess the ability of their client's placement to meet his or her needs with reference to location and size, CSC's typically gave the following kinds of responses.

> This home is adequate but a therapeutic foster home is more ideal.
>
> Ideal, five other residents is a good number.
>
> It's a rooming house, it offers him an opportunity to have some peer relationships of his own choosing. The manager offers a sense of security.
>
> He'd get lost in a bigger setting. There's currently enough people at different levels that he should be able find a friend if he desires to.
>
> Great -- plenty of attention; warm, comfortable space; clean surroundings -- shares room with only one other person and provides a family atmosphere.
>
> It's too big in terms of the number of people in the residence however she needs a large structure to move around in her wheelchair.
>
> This home, despite its size, is really good. It has an excellent activity program.
>
> The location is excellent -- close to family. However, therapies are not currently available in this location.
>
> Family is too far away. Looked for a closer placement -- none were available.
>
> This home is centrally located, close to all community resources.
>
> Doesn't meet her needs -- the only thing they do is see that she gets to work daily. It's near her day program, that's about it.

> He likes living in a rural area so it meets his needs well. He likes space around him and doing outdoor work.
>
> Good location, within walking distance of everything.
>
> It's close to parents -- ideal.

When asked to assess their client's residential placement in terms of community integration and use of leisure time, CSC's generally gave responses such as the following:

> They work hard at integrating client into available community activities. They encourage volunteer activity with the client.
>
> Great, independently goes to regular community events.
>
> It's a rural setting -- there are no community activities. They do go to church suppers. Occasionally they take residents for rides or for ice cream.
>
> It's a big problem -- home doesn't involve residents in leisure time activity or socialization.
>
> There are many trips for shopping and into the community. They (the residents) are included in community activity as any member of a family would be.

The CSC's saw leisure time and community integration needs not met more frequently than did residential providers. When transportation needs were assessed as not met by CSC's and day program providers, these transportation needs were almost always linked with community integration and use of leisure time.

When queried regarding daily activities residential providers' responses gave the following picture: individuals come home from day programs and engage in leisure or social activities and/or watch television. Some people do chores and some go out for community activities. Most people eat supper at the same time every day. After supper, individuals tend to do

more community activities, such as: going for walks; to the movies; to church; visiting, than before supper. Many people watch television solely or in addition to other activities. Some people do chores, make phone calls or visit with friends.

Regarding the monitoring of the quality of services in class members' homes and day programs. CSC's gave a variety of responses. Many visit homes and programs as often as once or twice a week, others visit once or twice a month. During their visits, CSC's sometimes observe and talk with their clients. Sometimes they visit when clients are not there and talk informally with residential and day program staff. Many CSC's review Individual Program Plan objectives with residential and day program staff. The following are some of their responses:

> I meet periodically in the home with the activity worker and observe her in action. I discuss with the home staff to see if she is coming regularly. I ask the home staff their impressions of this worker. I monitor any habilitation plans initiated by the worker. The communication is open and frequent (at least twice a month).
>
> I visit the home once a month. I determine how he is doing by interacting with him. I monitor as directed by the IPP and record this in his case record.
>
> I have an informal "kitchen table" discussion of the IPP goals and objectives. I speak independently with the client and residential provider to see if their perspective on an issue coincides. If I have an issue, I make a record in the action notes, discuss it with my supervisor and other CSC familiar with the home. (Regarding the day program) I monitor the quality by the program's following through on goals. I make an observation by attending the program while the client is at work. I interview client and staff members about their attitudes in relation to the program.
>
> I make bi-monthly visits. I write all pertinent information in the action notes. I get reports from the program quarterly.

> I visit every 6-8 weeks in a formal sense. I stop in informally every month. Anything significant I would document -- any crucial issue I'd discuss with the (BMR) Regional Administrator or Advocate.
>
> I visit the home once or twice a week. I have regular quarterly meetings with the staff. If there are problems I inform my supervisor. Usually I report quarterly to supervisor. I visit the day program weekly. I have facilitated communication between the home and program.
>
> I look to see how well dressed, out of bed, look at room. Feedback is discussed with the Regional Supervisor and the client's mother. I assume she's getting a quality program -- seen as how much she's getting out of it.

The majority of class members surveyed are not, according to their CSC's, restrained by physical or chemical means. Typically, chemical restraints are used more frequently than physical restraints, although there were few reported instances of either. Several CSC's responded that they did not know whether or not their clients were subject to physical or chemical restraints. The following are examples of their responses:

> Psychotropic medication is a restraint. (The reason for using it is) to maintain socially acceptable behavior and functioning. (The procedures used involve) consultation with medical and psychiatric professionals (who) prescribe dosages and frequencies arrived at based on client's reporting of optimum effects.
>
> (It's) monitored every 90 days by a psychiatrist and seen bi-weekly by a mental health nurse. Medication review would indicate behavior change plan.
>
> Client is restrained to wheelchair by a folded sheet. It is doctor approved as well as suggested by the physical therapist. The advocate has been advised. This is a medical as opposed to behavioral restraint.

According to residential providers, all class members can use their rooms whenever they want to. In all but a few instances, according to residential providers, individuals are allowed to visit privately in their rooms with

friends. More restrictions are placed on visiting with friends of the opposite sex.

Very few of the class members surveyed voted in the last election, according to residential providers.

Day program providers involved with the class members surveyed were not consistently familiar with M.R.S.A. Chapter 186-A (Maine law outlining the civil rights of the mentally retarded). Some had read it and a few use it to teach clients about their rights.

In terms of habilitation, residential providers reported that the majority of class members surveyed are learning things at home. Cognitive and/or vocational skills are most commonly being taught, activities of daily living are the next most common, leisure time and behavioral skills were also reportedly being developed.

For the class members living in foster, group, boarding and nursing homes, individual habilitation plans are usually either not available or not used, according to direct care staff. Between one-fourth and one-third of the class members surveyed living in these types of homes did have individual habilitation plans being used by direct care staff. Records of individuals' progress in habilitation are kept at least monthly by half of the residential providers and less than monthly by the other half.

In day programs, progress records are kept at least weekly for the majority of class members surveyed. In all but two cases, day program staff evaluated their own performance based, in part, on the progress of the individual class member.

Day program staff reported positive and constructive working relationships with all residential staff. Although in a few cases, the staff felt that

their goals for the class member under discussion differed from those of the residential staff, they still felt they worked together well in the individual's best interests.

Over half of the direct care day program staff felt that the staff-client ratio is adequate to meet the needs of the individual under discussion. The remainder felt that the staff-client ratio is too low while a few felt that it is too high.

The majority of day program providers interviewed reported that they did have time to do all of the required habilitation programs with the class member under discussion. Most of the residential providers concurred although the proportion of "yes" answers was not as great as with day program providers.

When asked to assess the homes of individual class members in terms of staff attitude, training and ratio, and habilitation, CSC's felt positive in some cases and negative in others. The following is a sample of their responses:

> More of a protective environment which meets his emotional needs for security but it is not a place that fosters independence and growth. The staff ratio is fine.
>
> (Their) intentions and responses are good. (Their) hearts are in the right place. (But they are) not trained enough for daily programming. The staff ratio is too low. (They can) meet habilitation needs with support.
>
> Staff attitude is one of sensitivity and caring and the client responds positively to them.
>
> Staff excellent, at least one-half have college education. (They have a) positive attitude and don't foster dependence. The staff ratio is excellent: one staff to three residents.
>
> Staff has low expectations of clients. They would prefer to "do" for their residents. No formal education in mental

> retardation. They have come to some BMR-sponsored inservice. The ratio is two staff to six residents. They have submitted a habilitation plan but generally speaking (have) no training on how to afford client the opportunity to do things for himself.
>
> He's well-liked by staff. Staff attitude has recently improved. New outlook on the developmental model and are implementing it. Formerly there was more concern for the nursing care.

Structured behavior modification programs which use aversive procedures are not being used. Techniques used to deal with behavior problems or the breaking of rules are described by providers as: use of positive reinforcement for appropriate behavior; attention to antecedent events (noting when an individual is becoming upset and changing something in the environment in order to preclude an outburst); counseling or talking it over; fining (loss of privilege); or being removed from the situation (asked to go to room). Some examples of behavior problems and the procedures used include:

> On occasion, she will push and shove another person in her way. Occasionally will hit or bite -- this is rarely done. We remove the other person from danger and calm her down. We'll then talk to her.
>
> Plugging the toilet with paper behavior, all staff would instruct her when she went into the bathroom not to plug, we respond positively and reinforced her when the behavior was no longer happening.
>
> Got isolated from people at workshop, it was determined that he needed a leisure time program rather than a work program. He was angry at other younger workers, didn't feel connected to them. Discussed alternatives, he wanted to retire, be around others his own age, problems cleared up right away.
>
> Approximately once a month he'll get angry at someone "picking on him". On these occasions he'll pick up something like a radio or lunch box and throw it at a wall. At these times he'd be sent to his room by staff, after a while the issue would be talked about with staff and him.

For about one-half of the class members surveyed living in residential facilities other than their own home or a supervised apartment, supper is served "family style". Of the remaining individuals most have portions served to them while a few eat "cateteria" or "buffet-style". One-half of the individuals living in residential facilities are allowed to use the kitchen anytime, one-fourth are allowed to use it at specified times, and one-fourth are never allowed to use it.

One-half of the class members surveyed in residential facilities schedule their own bath or shower, for the remaining half staff schedule it. Bedtime is chosen by over half of the individuals themselves. Curfew is most typically decided by staff or by the staff and residents together.

Most of the class members surveyed are involved in choosing and buying their own clothes either by themselves or with staff or family.

All but six of the class members surveyed had had an interdisciplinary team meeting within the last year. Of the six who had not, five had declined BMR services and one was school-age and had had a Pupil Evaluation Team meeting.

Most CSC's, day program providers and residential providers felt that for the class member under discussion, actual needs were addressed at the IDT meeting and are reflected in his or her current Individual Program Plan. Day program providers and residential providers in all but a few cases saw the Individual Program Planning process as a meaningful opportunity to share ideas and goals regarding their clients.

More than half of the day program and residential providers felt that all who needed to attend the IPP meeting were there. Of those who didn't

feel everyone needed was in attendance, most were referring to family or other service providers. Most of the individual program plans carried out at day programs for the class members surveyed are based on goals set at IPP meetings.

Most of the CSC's and residential providers were able to assess current level of progress for the individual under discussion specifically and objectively. Several CSC's and residential providers could describe it only vaguely and subjectively while a few were not able to assess the individual's current level of progress.

Day program providers were asked to describe progress the class member under discussion had made. The majority were able to describe progress, most of these gave specific, measurable indices of progress while only a few had seen no progress or didn't know if any had been made.

In making one year projections of growth for the individual under discussion, more than half of the CSC's and day program providers were able to make specific, measurable projections which reflect progress and growth. Residential providers were more likely to make vague one year projections. Some CSC's, day program providers and residential providers were not able to make one year projections. A few saw no progress possible for the individual under discussion in one year.

CSC's, day program providers and residential providers were usually able to make five year projections although many of these were vague. Several were not able to project and only one of each saw no progress possible for the individual under discussion in five years. (One of the class members surveyed had Alzheimer's disease which probably accounts for the inability

of providers to project progress for him.)

When asked to state a reason for any lack of progress on the part of the class member under discussion, day program providers most typically attributed it to the teaching strategy or to lack of attendance or low staff ratio. Very few saw it as meaning that the class member is lazy, has a poor attitude or can't learn.

Most day program providers assess the progress of class members surveyed objectively using criterion-referenced testing. A few assess subjectively and a few not at all. Residential providers were more likely than day program providers to assess individuals subjectively and several did not assess at all.

Residential providers most typically see themselves as "friends" or "best friends" with the class member under discussion. Other ways they characterize themselves in relation to the individual are as "teacher" or "teacher-friend" or "mother/father" or "one of the family". Many said they felt love, warmth and closeness to the individual under discussion. In only one case was the response to this question devoid of any nurturing quality.

When asked to describe his or her skills as a teacher, many residential providers felt they are adequately or well prepared. Some felt that they don't teach anything. The following are some typical responses to this question:

> I need more education. I'm prepared to teach them to cook and perform other ADL skills but I need help to learn how to deal with behavior problems.
>
> I had to learn a lot, BMR helped, though at first I didn't like it.

> I use trial and error a lot -- I look to see what works and use it. It's real satisfying to see what works. If it doesn't work I try something else.
>
> I don't teach anything. I am an aide and I correct his behavior. A teacher is someone who teaches -- I don't.
>
> Well prepared because of the relationship we have with him. We teach him everyday living which we're able to do well.

Almost one-third of the class members surveyed use psychotropic medication. This issue is usually but not always addressed at IDT meetings. CSC's report few "drug holidays" usually citing medical contraindication as a reason for not having one. When queried about the effects of medication on the habilitation of the class member under discussion, day program and residential providers reported no negative effects.

The majority of class members surveyed have their own dresser, a few share one with a roommate. More than half have their own closet, of the remaining individuals most share a closet with one other person while a few share a closet with more than one other person. Only one class member surveyed did not have a personal storage area.

Twenty-seven of the class members surveyed were interviewed. Some were able to answer all of the questions, others answered some questions but not others. Clients were interviewed privately, in one case a sign language interpreter was present during the interview in order to translate the individual's responses. Caution must be used in interpreting the results because of possible lack of validity and reliability in the responses of informants with mental retardation, which has been clearly demonstrated by Sigelman (1980).

When asked about people they lived with, all but one of the individuals stated that they liked them and could talk with them. The exception did not like any of her house-mates. When other residents were older or younger than the person interviewed this did not seem to be a problem. Most felt that the people they lived with could do about the same things that they could do. Some said that they could do more than other residents and that they felt good about that.

> He can't cook like I can, he has a hard time reading, he helps me with the housework.
>
> I like the people I share my life with.
>
> Mary is my roommate and closest friend. John is like a brother -- he drives me crazy!
>
> We talk about anything, usually what we want to do.
>
> The people I live with are nice and fair.
>
> I don't like most of them too well, they get on my nerves, I like to be alone.
>
> They are my friends. They help me and work with me.
>
> I love them all, they're my family.
>
> I feel sorry for those who can't do what I can do.

The majority of people who want to go to church are able to go as often as they want. Three people stated that they couldn't. Most people stated that they have a quiet place to pray if they want to, three said they did not. No one stated that they had to go to church if they did not want to.

> We go to church whenever (home operator) is able to take us -- when she doesn't have too much to do.

I stay in bed if I don't feel like going.

I sit in a chair in my room and think about things, like the good Lord.

Every Sunday I go to church.

When asked about receiving and sending letters, most of the individuals surveyed stated that they opened the letters first and in many cases a staff person or a friend would help them read the letters. A few people stated that staff opened the letters first. Of those who send letters, most stated that staff helped them write letters or checked them for errors. A few people are able to send letters by themselves.

When asked about having friends come visit and whether they were allowed to visit privately in their rooms, about half of the people interviewed said that they did have visitors. Almost one-third of the respondents said that they could have either men or women friends visit them privately, in their room. The remaining half of the individuals said that they have no friends who come to visit them. For the people who do have friends come to visit, the following are some typical responses:

I call them (friends from the workshop). They can visit in the living room. Nobody in my bedroom.

(I) call them up. Spend some time with him, watch T.V. or go for a walk. I have my apartment to visit. Male or female friends can come to my home.

I call them to come visit me. They visit me in my bedroom or in the family room. If I wanted to be alone I'd visit in my room.

Of the 23 responses regarding use of the telephone, over half said that they are able to make calls anytime by themselves. Most of the remaining

ask staff to help them. Only two said that they are not allowed to use the telephone at all times and one person said that he doesn't have anyone to call.

Respondents were asked to show the interviewer their clothes. Interviewers observed that the majority had adequate wardrobes including winter coat, boots, hat, mittens or gloves, warm socks, raincoat, "dress-up" clothes and outfits for work. The remaining individuals were missing at least one of the above mentioned items.

When asked to describe the jobs or chores that they do around the house, most individuals mentioned keeping their rooms tidy or making their beds. Other jobs or chores mentioned include:

My laundry
Pick up the mail
Feed the goats
Pick up the eggs
Stack wood
Bring wood in
Dust the living room
Vacuum the living room
Wash and/or dry the dishes
Help buy the groceries
Set the table
Clean the bathroom
Sweep the floor
Take out the garbage
All chores involved in keeping up an apartment
Prepare meals
Shovel snow
Clean the barn

All but two of the individuals said that they did not get paid for chores, a few mentioned that they saw this work as helping. One individual stated that he does get paid for outside work and cleaning the barn, another said that she gets paid but wasn't sure how much.

Interviewers showed respondents copies of their Individual Program Plans and asked questions about the meeting. One-third of the individuals made no response to this question or didn't remember the meeting. The remaining individuals remembered the meeting. The following are some of the comments made regarding the meeting:

> The meeting was good.
>
> (Named people at meeting). They talked about how I was bad. I have to be good. I didn't say anything.
>
> I didn't mind it.
>
> Talked about what I would do for school or work and the hospital.
>
> I got to talk about what I wanted to talk about.
>
> Talked about everything, goals.
>
> Talked about me and how to help me. Kind of liked it and kind of didn't.
>
> I don't like being around my social worker or people like that, they make me nervous. They didn't give me a chance to talk, they kept asking me questions.
>
> I talked about wanting my own guardianship. I talked about handling my own money. The other people said they'd keep me on the State.
>
> I thought the meeting was pretty good. I talked about wanting to move to (another group home) and to (another workshop).
>
> Talked about the workshop. They said because of my medical problem they didn't want me. I didn't say too much because they didn't ask me. I was told to keep still unless a question had been asked me.
>
> The meetings were good, they talked about me and how I liked it here. I talked about how I behave myself.

When asked to describe the way they felt about the home they were living in, most people who responded said it is just the right size, a few people stated that their home is too big. When asked what things they liked about the home, people gave a variety of responses such as:

> It's good living here, it's good for me.
>
> I like the country. I like putting things up on the walls.
>
> We go out a lot with (the home operator).
>
> I like to cook.
>
> I kile the house. It's nice and warm.
>
> It feels nice having my own apartment.
>
> I like (the home operator). We do a lot of things.
>
> I do a lot of things.
>
> It's near my father and friends. I love it.
>
> I like doing my laundry.
>
> There's nothing I like about it.
>
> It's my home. I like the people in it, they are all lovable. Sometimes I'd like to break away though.
>
> I like (the home operator).
>
> I am happier here, not many fights, the people get along here. I like us all coming together for breakfast.
>
> I like everything. It's pretty.

Many people, when asked about things they did not like about the home, said there was nothing they didn't like. Those who did have things they didn't like gave responses such as:

I came here a long time ago and I don't like still being here.

I don't like to go on long rides, especially to the workshop.

There's a lot of racket in the morning.

It's too big. They tell me to get dressed. It's cold in the house.

I don't like taking showers.

Sometimes I'm lonely.

I can learn but the way they talk you'd think I couldn't learn anything.

I don't like getting the wood in.

In response to the question "If you could live somewhere else, where would it be?", a number of people gave no response or didn't know. Respondents gave a variety of answers: to stay right here; to live with family or nearer to family; to live in an apartment; to move to a group home; to return to Pineland Center; or to move to a smaller place.

Due to limits imposed by time, distance, and availability, family members for only seven class members surveyed were interviewed. Six of those were either living with the individual or very closely involved in his or her life. One parent lived about an hour away from his son but had not visited him for a long time.

## DISCUSSION AND RECOMMENDATIONS

This evaluation sought to determine the degree to which normalization and habilitation are a real part of the lives of class members which are the two major themes of the standards in Appendix B.

The results of the survey indicate that the living, working, and learning experiences of class members adhere to these standards.

The picture that emerges is one of people living in smaller residences. They are, if able and willing, getting up early and going to day programs outside their homes. They are learning things at home and are involved in various types of activities.

The findings in this survey affirm the observations made by Gollay, et. al. (1978) in their report of a survey of 400 deinstitutionalized people with mental retardation all across the country:

> In many ways, the experiences which they described were not unique -- they did not differ from the kinds of experiences one would expect of "normal" people in the community. Study group members spent time in their homes, went to work or school, watched TV, went shopping. Like most people, they were content with some aspects of their lives but dissatisfied with others. They encountered certain problems and tried hard to cope with them. (p. 159)

Another way of evaluating the normalization possibilities available to these individuals is to look at the size of the living unit, as this has been demonstrated to have a significant impact on normalization (Baroff, 1980; Hull & Thompson, 1981; O'Connor, 1976). The trend toward smaller residences apparent in this survey gives evidence of more possibilities for normalization in the lives of class members.

As Baroff (1980) points out, it is the possibilities for "individualization" which probably creates the more normalizing quality of smaller homes: "Individual attention, privacy, personal possessions and greater freedom but also greater responsibility -- all of these are easier to provide in settings where numbers are small" (p. 114). These "individualization possibilities" seem to be available to most, if not all, class members surveyed, evidenced in the importance and meaningfulness of the Individual Program Plan process for direct care staff and case managers. Privacy, possession of personal space and belongings, and opportunities for individual attention because of appropriate staff attitudes and ratios, are also in evidence.

Direct-care and case manager staff attitudes toward and knowledge about their clients provide important insight into the daily lives of the clients. Surveying staff involved in the day-to-day experiences of clients is one of the ways of evaluating "quality of life" for these individuals (Pratt, Luszcz, Brown, 1980). The trend for direct care and case management staff surveyed to hold a "proactive" set of attitudes and knowledge gives evidence of a "quality of life" in which habilitation is stressed.

Ziarnik (1980) defines "proactive" direct care staff as those who know the client presently, are able to perceive the client in the future, and who work with and for the client. That the staff surveyed can be described as proactive is evidenced by: a general ability to assess client's progress or current level of performance; ability to make projections about the future; positive feelings about their relationship with clients expressed by residential providers; and day program providers evaluation of their own

performance based on client progress and their assessment that lack of client progress is usually due to something in the environment that can be changed.

Based on this survey, this auditor finds the Defendants to be in compliance with the provisions in Appendix B of the Pineland Consent Decree. The following recommendations are not intended to represent reservations regarding that finding.

1. Procedures used to monitor the quality of services for class members do not seem to be as structured and well-defined as they need to be. As more class members move back into the community it will become even more necessary to analyze the frequency, content and documentation of home and agency visits. Obviously, efficiency and cost-effectiveness are important because the channeling of resources into monitoring must be balanced with the channeling of resources into the direct-care services to which the monitoring is directed. Also, homes and agencies would have more realistic and consistent expectations of case managers were their roles and functions to be more clear. Input regarding the monitoring process should be solicited from homes and agencies in order to maintain a productive partnership in the business of providing quality services for people with mental retardation.

2. Crisis intervention services should continue to emphasize prevention and to de-emphasize the use of state institutions. The development of proactive direct care staff is an important step in this direction. More empirical data regarding situations requiring crisis intervention services would allow BMR staff to analyze variables contributing to or mitigating these crises. High-risk situations could then perhaps be avoided in some cases.

3. Inservice training regarding psychotropic medication, especially possible side effects, should be provided for all BMR case managers and their supervisors. Repeated reminders to psychiatrists and physicians regarding Decree requirements for "drug holidays", such as that given by Commissioner Concannon, may provide the impetus for the medical community to examine procedures for the use of psychotropic medication.

4. Methods to enhance social integration and provide leisure time opportunities should continue to be examined. The statement by many of the class members interviewed that they have no friends with whom they visit is a sad one. Salzberg and Langford (1981) suggest some alternatives including a companion or friendship model which originated in the Nashville-Davidson County area of Tennessee. This is certainly a difficult problem to address, but, given the creative and unique programs already established in Maine, is not an insurmountable challenge!

5. The Individual Program Planning Process is an excellent one. Especially important is the ongoing self-evaluation built into the process. The general enthusiasm from direct care and case management staff regarding the process confirms its appropriateness. There seem to be some concerns voiced by class members regarding the meetings. Perhaps a short interview with each client regarding his or her meeting right after the meeting would provide some "consumer" input to the self-evaluation. Adherance to the procedures set forth in the 1983 Individual Program Plan Manual would meet and even exceed the Standards set forth in Appendix B (omitted from this summary).

6. All staff working with people with mental retardation should be aware of their clients' legal rights in order to protect these rights and to function as advocates when necessary. Knowledge of the rights set forth in Chapter 186-A and Chapter 229 should be strongly emphasized through ongoing inservice training.

**Maine Department of Mental Health and Mental Retardation**

# Pineland Center

Box C, Pownal, Maine 04069 (207) 688-4811

EXHIBIT C

JOSEPH E. BRENNAN
Governor

KEVIN W. CONCANNON
Commissioner

RONALD S. WELCH
Bureau Director

GEORGE A. ZITNAY
Superintendent

September 7, 1983

Lincoln Clark
Special Master
United States District Court
Portland, Maine 04112

Dear Lincoln,

I am writing to provide you with up to date information regarding Pineland Center since its discharge from Federal Court jurisdiction on September 18, 1981.

Many positive changes have occurred at Pineland Center since then. The discharge from the Court served as a recognition to the staff for a job well done. This recognition provided new motivation to the staff to continue to provide and to create new services and programs for the multiply handicapped, mentally retarded persons residing at Pineland Center. Staff at Pineland Center were very pleased with the recognition of the Court. This in turn led to an improvement in staff morale.

As you know, Pineland has continued to monitor all the provisions contained in Appendix A of the Consent Decree. Additional monitoring has been conducted in the form of monthly reports and site visits by outside experts to review Pineland Center services, programs and the facility.

During the last review conducted by the Department of Human Services of the Intermediate Care Facility for the Mentally Retarded program at Pineland, the team from the Department of Human Services complimented Pineland for the best review to date. There were fewer deficiencies than ever. Those deficiencies that were noted were of a minor nature.

In addition to the external review by the Department of Human Services, community providers of services to the mentally retarded came to Pineland to review three of the day programs and have found all of our programs to be of high caliber.

Pineland has received full three year accreditation by the Joint Commission on Accreditation of Hospitals.

I am pleased to say that throughout the monitoring process a Quality Assurance program has evolved. This program involves all departments at Pineland and uses the problem identification and problem solving method.

The environment at Pineland continues to be improved. A new unit for handicapped individuals was opened at Federated Apartment III. This created a six bed apartment. The house used for the Superintendent in the past is now utilized for the residents and clients of Pineland Center. Doris Anderson Hall has been renovated and other improvements throughout Pineland have been completed.

The Behavior Stabilization Unit has been established at Pineland to serve as a short-term specialized treatment facility for mentally retarded people with behavioral problems. This unit acts as a back-up and support to the community system. Future plans for Pineland Center will bring the Center closer to becoming a short-term specialized resource center. Planning is underway for the development of a program for severely impaired infants and young children, for individuals diagnosed as pervasive developmentally disabled, and for the nonadjudicated mentally retarded offender.

Since the release from Pineland Center of Federal Court jurisdiction, Pineland has received many visitors from throughout the United States, as well as from Sweden and Canada.

Pineland Center staff have been called upon to serve as consultants to Massachusetts, New Hampshire, New York and West Virginia as well as in community programs throughout Maine. Pineland Center is a model for others.

It is rewarding to report these accomplishments to you and to let you know that Pineland Center will continue to make progress and to improve services to Maine's mentally retarded and developmentally disabled citizens.

Sincerely,

George A. Zitnay

George A. Zitnay

GAZ/eas

EXHIBIT D: AUDITING OF DECREE STANDARDS

I. OVERVIEW.

The Department of Mental Health and Mental Retardation, through the Bureau of Mental Retardation, will initiate at least annually an independent review of compliance with standards contained in Appendices A nad B of the Consent Decree entered in Wuori, et al. v. Concannon, et al. The review will take the form of an audit by a third party or parties qualified by profession to perform such an audit.

II. TOPICS FOR REVIEW.

A. Notice

1. Prior to commencement of the review process, the Department of Mental Health and Mental Retardation shall give notice to the intended review and of the opportunity for a public hearing if such a hearing is scheduled or requested.

2. At least 20 days prior to commencement of the review process, the Department of Mental Health and Mental Retardation shall:

a. Issue a press release and cause notices to be published in the major daily newspapers of the State of Maine and issue a second notice in the same manner at least 10 days before any scheduled public hearing;

b. Post notices in the central office of the Department of Mental Health and Mental Retardation at Pineland Center and in all regional offices of the Bureau of Mental Retardation; and

c. Notify by mail the Consumer Advisory Board, Pineland Parents & Friends, the Maine Committee on the Problems of the Mentally Retarded, the Development Disabilities Council, the Maine Association for Retarded Citizens, Advocates for the Developmentally Disabled, and any other person or organization requesting that formal notice be mailed to it or them.

3. The notice shall:

a. State the purposes of the review;
b. State the manner and time within which topics for review and the names of candidates for auditor may be suggested; and
c. State the time and place of any scheduled public hearing; or

d. If no public hearing is scheduled, state the manner and time within which a public hearing may be requested.

B. WRITTEN SUGGESTIONS.

1. Written suggestions of topics for review (e.g. decree areas, types of services, geographical areas, etc.) and candidates for auditor may be filed at any time with the Bureau of Mental Retardation. All Suggestions shall be acknowledged in writing and accompanied by a copy of this document.

2. The Bureau of Mental Retardation shall maintain a current record of all written suggestions received subsequent to any prior audit. The record shall include:

a. The date received;
b. The name and address of the person or organization making the suggestion(s);
c. Whether a public hearing is requested; and
d. A brief statement of the nature of the suggestion(s).

3. The record of suggestions received shall be made available for inspection and copying in the Central Office of the Department of Mental Health and Mental Retardation. Immediately following the expiration of the time set for the receipt of suggestions, copies of the record of suggestions shall be posted in the Central Office, at Pineland Center and in the regional offices of the Bureau of Mental Retardation and shall be provided to any person or organization upon written request.

C. PUBLIC HEARING.

The Director of the Bureau of Mental Retardation may hold a public hearing in accordance with the notice issued to receive and discuss suggestions for topics for review and candidates for auditor. The Director shall hold a public hearing if requested to do so by any five interested persons after issuing a notice as required above and to all persons and organizations submitting suggestions.

D. SELECTION OF AUDITOR AND TOPICS.

1. The Commissioner of the Department of Mental Health and Mental Retardation, with the advice of a representative of the Consumer Advisory Board and a third person chosen jointly by the Commissioner and the representative of the Consumer Advisory Board, shall select the person or persons to conduct the review and the topic(s) to be reviewed. Neither the representative of the Consumer Advisory Board nor the third person chosen jointly shall be a person employed by the State of Maine.

2. In making the selection of topics for review, persons specified in the preceding paragraph shall consider those suggestions which were made most frequently or concern particularly severe or on-going problems.

3. In making the selection of the auditor(s) to undertake the review, the persons specified above shall select a person or person(s) familiar with:

a. the subject matter areas of the topics chosen for review;
b. the policies, standards, and procedures governing the topics for review including the Consent Decree, and
c. the appropriate techniques necessary to perform a professionally acceptable audit.

III. AUDITOR'S REPORT.

A. The auditor(s) shall prepare a written report which shall include:

1. A description of the topics audited;
2. A description of the policies, standards, procedures and techniques employed in conducting the audit; and
3. The auditor's findings, conclusions and recommendations for corrective action required, if any.

B. The auditor(s) may report findings collateral to the topics investigated. These collateral findings shall have no bearing on the question of compliance with decree standards, but shall be considered as any other suggestions in a subsequent review process.

C. The auditor's report shall be made available for inspection and copying at the central office of the Department of Mental Health and Mental Retardation at Pineland Center and at all regional offices of the Bureau of Mental Retardation. The auditor's report or a summary of it shall be mailed to all persons or organizations receiving the initial or any subsequent notice.

IV. CORRECTIVE ACTION.

A. If the auditor's report suggests the need for corrective action, the Department of Mental Health and Mental Retardation shall develop and implement a plan of correction which fairly addresses the findings and conclusions of the auditor's report. The plan of correction shall be completed within three (3) months of receipt of the auditor's report and shall appropriately identify time frames and other resources required to implement said plan.

B. Any plan of correction developed herein shall be made available for inspection and copying at the central office of the Department of Mental Health and Mental Retardation at Pineland Center and at all regional offices of the Bureau of Mental Retardation. Any plan of correction shall be mailed to all persons or organizations receiving the initial or subsequent notice.

EXHIBIT E: ROLE OF THE CONSUMER ADVISORY BOARD

(For inclusion with "Annual Audit of Decree Standards" in the Court Order discharging the Defendants.)

1. C.A.B. Functions. The primary function of the Consumer Advisory Board (CAB) shall be to recruit, approve, train, supervise and support correspondents for Bureau of Mental Retardation (BMR) clients. The BMR shall also recruit correspondents as requested by the CAB.

In addition, the CAB shall approve behavior modification programs for clients, review quarterly reports of the BMR Director on his disposition of advocates' recommendations regarding alleged abridgements of the rights of clients, receive and evaluate reports of alleged dehumanizing practices and include recommendations remedying these practices in its quarterly reports, perform the role designated for it in the Annual Audit of Decree Standards, and submit at least a quarterly report to the Commissioner on its accomplishments and observations on the progress and problems in the areas of its concern.

Performance of the above functions shall not be to the exclusion of other CAB responsibilities specified in Appendices A & B of the Consent Decree of July 21, 1978. This document specifies the role of the CAB with respect to Class Members as defined in the Consent Decree.

2. Organization. The CAB shall consist of 11 members appointed by the Commissioner for staggered terms not to exceed two years. At least three nominations to the Commissioner shall be made by majority vote of the CAB at least 30 days prior to the expiration of member's term. If the nominations are unacceptable, the CAB shall submit three alternative nominations. A member whose term has expired may be elected by majority vote to continue as a member until the Commissioner appoints a successor.

Six of the members of the CAB shall also serve as chairmen of six Regional Committees of the CAB. The Regional Chairmen shall appoint as members of the Regional Committee at least four correspondents who reside or work in the region, for staggered two year terms.

The CAB shall appoint an Executive Secretary with the advice and consent of the Commissioner for a term of two years. Subsequent appointments shall be made thirty days prior to the expiration of the term. The appointment shall be for at least half time for the Executive Secretary excluding any time spent on the training of correspondents.

The duties of the Executive Secretary shall be specified by the CAB.

3. Information. A member of the CAB, in accordance with CAB policy, shall have direct access to all living and program areas and to all records directly related to resident or client care, other than personnel records, and to the personnel of any institution, facility, or agency administered by the BMR or where the client of the BMR resides or participates in a day program.

Matters may be brought before the CAB by any person including CAB members, BMR clients, residents of Pineland Center, parents, guardians, employees of the Office of Advocacy, Pineland Center, the BMR, and nay other State employee. No individual shall be subject to counseling, discipline, or reprisal for bringing a matter to the attention of, or for giving information to, the CAB.

4. Finance. The BMR shall provide facilities required by the CAB. The BMR shall reimburse the reasonable expenses of the CAB members, Regional Committees and Executive Secretary, and the salary of the Executive Secretary (unless otherwise paid by the BMR), for carrying out their responsibilities. Their expense vouchers shall be submitted to the central office of the BMR.

EXHIBIT F:

May 20, 1983

The Honorable Donald V. Carter
House Chairman, Appropriations & Financial Affairs
Box 544
Winslow, Maine 04902

Dear Representative Carter:

As you know, the State has applied for a Medicaid waiver to provide for personal care services for the mentally retarded. It would enable the State to meet the standards in the Pineland Consent Decree of 1978, and thereby qualify for dismissal from the Court's supervision. A great deal of money is involved - $10,500,000 over the next three years.

The development of the waiver application has been agonizingly slow but, after a year's labor, the outlook for its approval is very good - hopefully in July. The problem now is not to get the money but to be ready to spend it promptly and effectively. Delay would be unnecessary and lamentable. Many residents of Pineland have been waiting a long time to transfer to the community - 227 residents have been there over 15 years. Moreover, <u>each month's delay would result in a non-recoverable loss of over $135,000</u>.

Since the Office of the Special Master does not have the technical resources to monitor the State's implementation plans I am asking a small ad hoc committee to assist me in this task. A listing of this committee may be found at the end of this letter.

Because this waiver application involves two State departments which may have somewhat different priorities, I feel it is vital that some oversight be provided to ensure that the funds potentially provided in the Part II Appropriatons Act be effectively deployed on a timely basis. Perhaps additional language in the Part II Appropriations Act requesting a report to the Appropriatons Committee on a quarterly basis would be effective in focusing attention on implementation of this waiver if approved at the federal level.

A waiver implementation plan and timetable has been developed by the two departments. Should implementation be delayed by any possible bureaucratic inertia I would like to hereby request potential access to the Appropriations Committee should the need arise. I certainly hope that such access would not be required but do want to inform you of the existence of this ad hoc committee which has as its specific charge the timely implementation of the Medicaid waiver. I know that your Committee has responsibility for the entire range of state funding and hope that this ad hoc committee could be of assistance to you in oversight of this specific area which is my particular concern as Special Master of the United States District Court.

Thank you in advance for your consideration.

Sincerely,

Lincoln Clark
Special Master
United States District Court

cc: Edward Bouchea, Mickey Boutilier, David Gregory, David Huber, Mike McNeil, John Menario, Frank Wood, ex officio representatives of Dept. of Mental Health and Mental Retardation and Dept. of Human Services.

EXHIBIT G

BDM

BERRY, DUNN & McNEIL / Certified Public Accountants
96 Harlow Street / Bangor, Maine 04401 / (207) 942-6343

Lincoln H. Clark, Federal Special Master
Portland, Maine

We have prepared the accompanying summary of our full report to you dated April 20, 1983 concerning the potential for a transsitional employment program for qualified mentally retarded citizens in the Maine nursing home industry (TEP/NI). Our engagement was designed to; 1) determine if there was sufficient employer interest to warrant pursuing the development of a TEP/NI program; 2) identify the associated costs and financial incentives for such a program; and 3) provide recommendations for consideration of future developers of a program.

This summary is intended solely for your use as an Exhibit in your report to the Federal Court. This summary does not include all the Appendices, the detail information concerning the assumptions utilized in analyzing the available data or the limitations in the scope of our engagement and, therefore, is not complete. No conclusions should be formulated from this summary report without a review of the complete report dated April 20, 1983. All program concepts and cost data provided in this report are presented solely for illustrative purposes, and are not intended to depict the specific terms, conditions, or projected results of any future program.

August 31, 1983

Berry Dunn - MTH

## CONCLUSIONS

A successful TEP/NI program could be developed that would provide the desired employment opportunities for qualified mentally retarded participants.

### Financial Benefits to Employers

There are sufficient potential financial benefits to encourage employers to participate in a TEP/NI program:

- Department of Labor certificates permitting employers to pay handicapped employees based on productivity.

- Targeted Job Tax Credits providing Federal income tax credits for 50% of the first year wages and 25% of the second year wages (up to $6,000 per year of total wages per employee) paid to program participants.

- Potential lower costs associated with retaining TEP/NI program participants to replace higher paid experienced employees who terminate their employment could provide cost savings to the employer. There are incentives incorporated in the Maine Medicaid system of reimbursement that benefit providers who are able to achieve such savings.

## Employer Interest

There is sufficient interest in the program by potential nursing home employers to warrant consideration of future development of the program. Based on a limited survey of clients of our firm, 34% of those contacted expressed a positive interest in employing two qualified program participants, assuming the program was structured to adequately address the employers' operational concerns. There are approximately 140 nursing homes in Maine, so the projection of our survey results indicate there may be 47 facilities who would participate resulting in the potential for 94 placements if each interested facility accepted two program participants. Successful initial implementation of the program could generate more extensive participation.

## Concerns of Employers

Employers considered the following to be essential elements of any future program:

- Employer must retain the authority to select the specific program participants to be employed, and the authority to dismiss these participants from employment in accordance with the employer's normal policies.

- Pre-employment training must be sufficient to prepare program participants for performing the tasks to which they will be assigned, and provide them with the general work habits needed to work productively with other employees.

- The developer/sponsor must be available on a timely basis for special supervision needs of the program participants, coordinating administrative details of the program, and resolution of periodic concerns of the employer.

- The employer must be able to obtain and retain employees through the program with no substantial increase in bureaucratic paperwork and reporting requirements other than that which would be applicable to other employees.

Bureau of Mental Retardation (BMR) and Bureau of Vocational Rehabilitation (BVR) Concerns

The concerns expressed by representatives of these agencies included:

- There will be a need for special supervision of individuals who qualify for participation in the program. It will be difficult to adequately provide this supervision with only two employees in each nursing home.

- There will be a permanent need for BMR case workers to maintain contact with the participants for non-work related matters. There will be no substantial cost savings related to the personnel resources of the BMR staff.

- There may be resistance by families who receive Social Security funds for the care of individuals placed in this program, since these funds will terminate if the participant is successful in retaining employment. They could exert a strong negative influence on the participant which could diminish the likelihood of his successful completion of the program. This must be taken into consideration in the selection of program participants and the pre-employment training.

- Considerable personnel and financial resources are committed to the existing network of sheltered workshops and day programs. Any new TEP/NI program must be designed so it is not competing with the existing network for available resources.

## RECOMMENDATIONS

To maximize the potential for success a future TEP/NI program should provide flexibility in employment arrangements to address employers' varied needs. The employers' initial perception of the program's integrity will dictate its fate. The support of BMR and BVR is essential to the effective development and implementation of the program, particularly with regard to identifying and training qualified employee participants. We recommend the following concepts be given consideration in the development of any future program:

- o A single organization (sponsor) should be selected to provide all pre-employment training, employer contact, employee placement, and post-employment supervision and follow-up. The centralization of the program within one organization will enable the development of a standardized program which should minimize employer confusion and program inconsistencies. It will also enable the concentration of available expertise toward the development of a strong program that could become diluted if more than one organization were involved.

- o The person (developer) representing the sponsor who will be the direct liaison with potential employers must be knowledgeable about the needs and objectives of the proprietary sector of the economy. The program must be designed to offer realistic financial benefits to the employers, and the employer must be convinced his personnel needs will be satisfied by program participants.

- o Representatives of BMR and BVR should be extensively involved in the formulation of the basic structure of the program and the selection of the specific organization to serve as the sponsor. Their involvement should ensure the program is structured in a manner that is compatible to the

existing network of day programs and sheltered workshops. The actual administration of the program, however, should be the responsibility of the sponsor and divorced from the bureaucratic environment.

- The program should be initiated in one area of the State to enable the sponsor to provide adequate supervision for employees placed in various nursing homes. The TEP/NI program will not have a sufficient number of employees in any single facility to warrant an inhouse representative of the sponsor for supplemental supervision. The distance between employers must be minimized to provide supervisory personnel available to each employer on a daily basis. Because of the availability of potential employers, the Portland, Lewiston, or Bangor areas should be considered for initial implementation.

- The involvement of potential employers will be maximized if the program is designed to provide flexibility for the developer and sponsor to design employment arrangements that fit each employer's specific needs and concerns. Three illustrative alternatives are:

    1. The employer immediately hires the program participant as an employee at 50% of minimum wage. The wages increase gradually as the employee's productivity increases. The cost of all payroll taxes and fringe benefits would be borne by the employer. Commissions would be paid to the sponsor by the employer, as well as supplements being paid by BVR and BMR to the sponsor. The employer would be entitled to Targeted Job Tax Credits on all wages paid to each employee for the first two years of employment. Appendix A is an illustration of this alternative.

2 The sponsor provides services to prospective employers using program participants on a fee-for-service basis. This fee-for-service arrangement would last for a specified period, at the end of which the employer could hire specific individuals who rendered services under the contractual arrangement. The employer would pay a fee to the sponsor while the services were provided by the sponsor which would cover the cost of salaries, payroll taxes and fringe benefits paid by the sponsor. The program participants would be employees of the sponsor until hired by the employer. The employer would not receive any Targeted Job Tax Credits until the program participant became an employee of the facility.

3 The sponsor could place individuals in a prospective employer's facility for a specified period at no charge to the employer. The employer would be required to provide an evaluation to the sponsor of the individual's productivity for the period, just as they would evaluate any other employee. At the end of the period, the employer could decide whether or not to hire any of the individuals participating in the program. All individuals would be employees of the sponsor during the trial period with all costs borne by the sponsor.

It will be possible for the sponsor to obtain a group certificate from the Department of Labor permitting the sponsor to pay less than minimum wage under this type of a program. It will also be possible for the individual employers to obtain individual certificates to permit them to pay participants less than minimum wage when employing program participants who perform these functions at less than "normal" productivity.

Numerous other specific arrangements could be more enticing to specific potential employers. The more flexibility incorporated into the program, the more employers' needs that can be addressed. This will expand the market for the program and enhance the possibility of the development of long-term viable employment opportunities.

## SUPPLEMENTAL INFORMATION

### Survey of Potential Employers

In January of 1983 we circulated a questionnaire to thirty-five nursing homes to solicit information concerning potential employer interest in a TEP/NI program. A brief explanation of the potential financial benefits to prospective employers and a skeletal illustrative program description accompanied the questionnaire. We also requested that respondents provide us with information concerning the nature of the fringe benefits offered employees. The questionnaire and related information utilized are included in the original report to the Special Master, but are not included in this summary.

Of the thirty-five facilities contacted, twenty-three responded, and twelve of these indicated a positive interest in participating in the program, assuming the detail requirements of the eventual program are satisfactory to them.

Participant's Insurance Coverage

It is envisioned that the program participants will all be clients of BMR or BVR. Accordingly, they currently receive the benefit of health and major medical insurance coverage through the Medicare and/or Medicaid programs. This coverage could continue for a program participant for at least six months while they participated in the TEP/NI program. However, those that are successful in attaining full-time employment through the program would lose these benefits.

Substantially all responding facilities provide basic health and major medical insurance. Approximately 50% of the responding facilities who expressed an interest in the program also provide disability insurance. The period of employment required before employees become eligible for coverage ranges from one month to three months for these programs. Most facilities indicated the employer bears all of the cost of the premiums for this insurance coverage applicable to a single individual.

APPENDIX A

# TRANSITIONAL EMPLOYMENT PROGRAM
# NURSING HOME INDUSTRY
# (TEP/NI)

## Preliminary Program Concepts and Financial Calculations for an Illustrative Model

### I Program Objective

- To develop a pilot program within the Maine Nursing Home Industry providing an opportunity for qualified mentally retarded citizens to develop work skills which will eventually enable them to retain a job in a competitive environment and be substantially financially independent.

### II Placement Objectives

- Place 2 employee participants (clients) per month for three years, a total of 72 placements.

- Place a minimum of 2 clients in each employer location.

- Provide sufficient financial and social incentives for the Bureau of Vocational Rehabilitation (BVR), Bureau of Mental Retardation (BMR), sponsors, developers and employers to participate and actively assist clients to master the skills necessary for them to become employees.

III Qualified Clients

- Clients of BVR or BMR

- Must complete BVR or BMR sponsored programming in a sheltered workshop or other activity center, which includes training in job seeking skills, work adjustment, work evaluation, etc.

- Must be recommended by the sponsoring workshop or activity center and approved by the representatives of BVR and/or BMR after an appropriate screening process.

IV Organizational Responsibility

- Sponsor(s) - either a new organization established to provide the pre-employment training cited above, or existing organizations performing these functions. The sponsor will be responsible for preparing and recommending BVR and BMR clients for participation in the program.

- Developer(s) - individual(s) responsible for:
  - Identifying prospective nursing home employers and placing clients with same.
  - Attaining Department of Labor certificates approving payment of wages less than minimum wage by employers.

- Obtaining necessary certificates for employer to claim Targeted Job Tax Credits for first and second year wages paid clients.

- Provide instruction and supervision to clients concerning employer's personnel policies and procedures.

- Confer with employer weekly for at least first six months of employment concerning clients work.

- Provide support services to client for first two years concerning matters such as living accommodations, Social Security benefits, etc.

- Employer - provides position in dietary, laundry, or housekeeping departments for client.
  - Specific functions to be performed by client to be determined by developer and employer.

  - Agrees to hire client for one month training period with option to extend training period for an additional five months at special wages (See Employer Costs). Wages paid for the six month training period will be less than minimum wage under a certificate granted by The Department of Labor. The specific amount of hourly

wage will depend on each employees productivity during the hours worked.

- If client is retained as employee at end of six months, wages increased to minimum wage.

- Agrees to provide fringe benefits, such as insurance coverage, to all clients in the same manner and under the same terms as such fringe benefits are provided to other employees performing similar functions within the framework of the employer's personnel policies and procedures.

- Agrees to pay all required payroll taxes and workman's compensation insurance.

- Employee Participants (Clients)

  - Responsible for conforming to employer's policies regarding attendance, working hours, safety regulations, dress code, and all other personnel policies.

  - Will work a minimum of 4 hours per day five days per week and a maximum of 8 hours per day five days per week during the first year of employment.

- Serious violation of the employers policies will be grounds for dismissal.

Financing

- Bureau of Vocational Rehabilitation - pays sponsor $280 for each placement.

- Bureau of Mental Retardation - pays sponsor $70 for each placement.

- Employer - pays sponsor 10% of total wages paid employee participant for the seventh through twelfth months of employment, and 5% of wages for second year of employment.

- Employee - pays sponsor 5% of second years wages.

- Sponsor - pays developer:
  1) $280 received from BVR for each placement at time of placement.
  2) $70 received from BMR for each placement at time of placement.
  3) 5% of employees compensation for second six months of employment..
  4) 5% of employees wages for the second year of employment.

- Employee receives an hourly wage based on the number of hours worked and the productivity during those hours in relation to other employees performing similar functions. The following productivity and rates are assumed for the illustrative model:

  1) first month - 20 hours per week worked, 50% productivity, 50% of minimum wage paid.
  2) second through sixth months - 30 hours per week worked, 75% productivity, 75% of minimum wage paid.
  3) seventh through twelfth months - 35 hours per week worked, 100% productivity, minimum wage paid.
  4) second year of employment - 35 hours per week worked, 100% productivity, 105% of minimum wage paid.

## VI Alternative Considerations

- If it is necessary to increase maximum potential compensation to either sponsor or developer in order to attract competent personnel and/or organizations, additional lump sum payments by BVR and BMR could be made at the end of six months (when client hired by employer) and at the end of one year (when client retained for second year by employer).

- If DOL has problem with employer paying commission to sponsor from sixth through twenty-fourth month of employment (no problem anticipated), salary paid to client could be increased and client could pay 100% of commissions. Additional salary increase would be eligible for Targeted Job Tax Credit for employer which would more than offset increased payroll tax cost.

- If clients are employees of sponsor during training period, and the nursing home does not hire the client after six months, the nursing home loses the credit they could have had on the first six months wages if the client had been employed by the nursing home.

- If the developer is employee of sponsor, and sponsor is exempt from Federal income tax under Code Section 501(c)(3), sponsor's employees can be exempt from Social Security tax. Developer would not have to have Social Security taxes withheld from his pay, thereby maximizing his net pay. If developer functioned as an independent contractor, however, he would be subject to self-employment tax regardless of the status of the sponsor and its employees for Social Security tax.

# Calculation of Employer's Cost Per Client for First Two Years of Employment Compared to Employer's Cost for Hiring Non-Program Employee

## Assumptions:

- o Client works 20 hours per week for the first month at 50% productivity. A DOL certificate is obtained to pay employee 50% of current minimum wage of $3.35.
- o Client works 30 hours per week for the second through sixth months at 75% productivity. A DOL certificate is obtained to pay employee 75% of current minimum wage of $3.35.
- o Client works 35 hours per week for the second six months of employment at 100% productivity and at the minimum wage of $3.35.
- o Client works 35 hours per week at 100% productivity for the second year of employment at an hourly rate of $3.52. (105% of the current minimum wage of $3.35).
- o Employer pays 10% of second six months wages, and 5% of second years wages to sponsor as commission.
- o Employer pays all required payroll taxes.
- o Cost of insurance programs and other fringe benefits would be the same for clients as other similar employees, so there is no cost differential that has been considered for these items.

## Employer's Cost per Client

1) Wages -

First Year

| | | |
|---|---|---|
| 1st mo. | = 20/hrs. x $3.35 x 50% x 52 wks ÷ 12 mo. = $144 x 1 = | $ 144 |
| 2nd - 6th mo | = 30/hrs. x $3.35 x 75% x 52 wks ÷ 12 mo. = $324 x 5 = | 1,620 |
| 7th -12th mo | = 35/hrs. x $3.35 x 52 wks ÷ 12 mo = $508 x 6 = | 3,048 |
| | | 4,812 |

Second Year

| | |
|---|---|
| 35/hrs. x $3.52 x 52 wks. = | 6,406 |
| Total wages for two years | $ 11,218 |

| 2) Payroll Taxes | | Year 1st | Year 2nd | |
|---|---|---|---|---|
| FICA | @ 6.7% | $322 | $429 | |
| Unemployment | @ 3.4% | 164 | 217 | |
| Workman's Comp | @ 24¢/$100 of salary | 115 | 154 | |
| | | $601 | $800 | 1,401 |

| 3) Commissions | | | |
|---|---|---|---|
| 1st year | 10% x $3,048 (last 6 months only) | $305 | |
| 2nd year | 5% x $6,406 | 320 | 625 |
| Total Cost | | | (A) 13,244 |

| Less: Targeted Job Tax Credit (JTC) | | | |
|---|---|---|---|
| 1st year | 50% x $4,812 -(20% x $2,406)* | 1,925 | |
| 2nd year | 25% x $6,406 -(20% x $1,602)* | 1,282 | 3,207 |
| Net cost for two years per employee | | | (B) $10,037 |

* Total wages must be reduced by the JTC claimed. Assumed employer is a corporation with an effective Federal tax rate of 20% to compute the tax on increased income due to reduction in salary expense by JTC.

Employers Cost Per Non-Program Employee

1) Wages

First Year

| | | |
|---|---|---|
| 1st mo. | - 20/hrs. x $3.35 x 52 ÷ 12 =$290 x 1 | $ 290 |
| 2nd mo. - 6th mo. | - 30/hrs. x $3.35 x 52 ÷ 12 =$435 x 5 | 2,175 |
| 7th mo. - 12th mo. | - 35/hrs x $3.35 x 52 ÷ 12 =$508 x 6 | 3,048 |
| | | 5,513 |

Second Year

| | |
|---|---|
| 35/hrs. x $3.52 x 52 = | 6,406 |
| Total wages for two years | $11,919 |

Employers Cost Comparison
Page

| 2) Payroll Taxes | | Year 1st | Year 2nd | |
|---|---|---|---|---|
| FICA | @ 6.7% | $ 369 | $ 429 | |
| Unemployment | @ 3.4% | 187 | 217 | |
| Workman's Comp. | @ 24¢/$100 of wages | 132 | 154 | |
| | | $ 688 | $ 800 | 1,488 |
| Total cost and net cost for two years | | | | (C)$13,407 |

| Comparison | Total Cost | Net Cost |
|---|---|---|
| Cost of non-program employee | (C)13,407 | (C)13,407 |
| Cost of program client | (A)13,244 | (B)10,037 |
| Cost savings to employer per client employee | $ 163 | $ 3,370 |

APPENDIX C

## Net Revenues to Sponsor and Developer Per Client Employee

| | Total Received | Total Paid to Developer | Sponsor's Net |
|---|---|---|---|
| Receipts | | | |
| BVR - at placement | $ 280 | 280 | - |
| BMR - at placement | 70 | 70 | - |
| Commission - first year | 305 | 152 | 153 |
| Commission - Second year | 640 | 320 | 320 |
| Revenue per client | $ 1,295 | 822 | 473 |

APPENDIX D

## Estimated Cost Savings to Bureau of Vocational Rehabilitation and Bureau of Mental Retardation Per Successful Client Employee for Year of Placement

| | |
|---|---|
| Estimated cost of sheltered workshop and activities program per year | *$6,000 |
| Cost per client placement | (350) |
| Cost savings - first year | **$5,650 |

* This assumes all other costs associated with client will be continued. To extent this is not true, additional savings may be realized.

** If client is successful and maintains position after first year, an amount of $6,000 per year thereafter will be saved for every year client is self-sufficient.

EXHIBIT H:

MEDICAL CARE DEVELOPMENT, INC.
11 Parkwood Drive
Augusta, Maine 04330

# PLANNING PROJECT FOR A STATEWIDE PROGRAM FOR THE PREVENTION OF DEVELOPMENTAL DISABILITIES/MENTAL RETARDATION

## PREFACE:

This report is to help The Maine State Planning Council on Developmental Disabilities determine the types of programs which can most effectively reduce the evidence of developmental disabilities in Maine. The project has not attempted to conduct prevalence studies, to design an evaluation process, to create an indexing or computerized tracking system, or to evaluate the quality of the numerous prevention efforts presently underway. An attempt has been made to research relevant literature, to gain the input of a wide variety of professionals and parties having direct involvement and/or interests in developmental disabilities and prevention, and to provide a suggestion for how the Developmental Disabilities Council can initiate a process of planning, coordination, and evaluation for preventing developmental disabilities within Maine.

The project should in no way deter the many fine efforts of prevention presently underway within Maine but rather proposes to build upon those efforts and to provide a new public focus for the prevention of developmental disabilities.

Medical Care Development is greatly indebted to the many professionals throughout Maine who participated in this study to

the Maine Planning Committee on Developmental Disabilities for funding the study and to state officials who freely gave of their time and ideas to move the study ahead.

# INTRODUCTION

In a report authored by Lincoln Clark, the Special Court Master concerning Martti Wuori vs. Kevin Concannon, one of his observations concerns itself with preventing mental retardation. Within the report it is stated,

> Mental retardation is a condition of many types and causes. Two types of programs are needed--treatment and prevention. Maine has won many battles to improve the treatment of mentally retarded, but Maine is losing the war against mental retardation. The major goal now should be prevention, not just better care of victims.(1)

There has been a heightened concern for the prevention of developmental disabilities in children. Studies have shown that the numbers and severity of disabilities can be lessened with a potential to alleviate the human concerns for the individual and families which accompany handicapping conditions. In addition there are large potential cost savings associated with reduction of institutionalization and other services for developmentally delayed and disabled and the increased earning power of the nonhandicapped individual.

There are three levels of prevention: primary, secondary, and tertiary. Primary prevention efforts attempt to avert the

development of the impairments before birth within a susceptible population, secondary prevention consists of early diagnosis of correctable conditions, and timely intervention to repair the condition. Tertiary prevention is concerned with persons already afflicted and subsequent attempts to limit the degree of disability and to foster rehabilitation.

There are a number of prevention strategies as outlined by Crocker in his "The Golden Twenty" listing (2). (See ATTACHMENT __ "Primary prevention strategies are those which are designated to eliminate the occurrence of the condition which causes the handicap".

His listing of primary prevention activities are as follows:

1. Rubella Immunization - to prevent the phenomenon of congenital rubella and its attendant morbidity.

2. Improved Prenatal Care - with concern for the pregnancy at risk, including improved nutrition, management of diabetes, and prevention of prematurity.

3. Special Care for the Premature Infant - as exemplified by the pediatric specialty of neo-natology and the newborn intensive care unit.

4. Genetic Counseling - for families in which there are known problems (such as Fragile-X syndrome, chromosomal translocations, etc.).

5. Advice Regarding Alcohol Intake During Pregnancy - for prevention of fetal alcohol syndrome.

6. Reduction of Environmental Exposure to Lead in Children - as pertains to both lead intoxication and increased lead burden.

7. Prevention of Kernicterus - by appropriate Rh-antibody testing and use of immunoglobulin.

8. Reduction of Childhood Accidents (Head Injury) - by attention to effective restraint in automobiles, and to other hazards.

9. Counseling and Education to Reduce Pregnancy in the Teen Years - with the attendant increased obstetric and social risks.

10. Efforts to Decrease Child Neglect and Abuse - utilizing support, education, and surveillance.

11. Health and Nutrition Education - designed to promote preventive and anticipatory care of children.

Crocker defines the secondary prevention activities as those "in which there is early identification of a relevant condition, and then an intervention to avert an outcome of retardation." His listing of secondary activities include:

12. Screening of Newborn Infants for Treatable Inborn Errors of Metabolism - with particular reference to PKU and galactosemia.

13. Newborn Screening for Congenital Hypothyroidism - followed by replacement therapy.

14. Amniocentesis in Circumstances of Advanced Maternal Age - for the prenatal diagnosis of chromosomal disorders (particularly trisomy 21), with a potential for pregnancy interruption.

15. Screening of Maternal Serum for Elevated Alpha-fetoprotein - as an index of neural tube defects.

16. Carrier Identification in Genetic Conditions - especially Tay-Sachs disease, to allow counseling regarding pregnancy.

Crocker's tertiary prevention activities which he defines as, "those which bring particular supports to children and families with ascertained problems, to minimize long-term disability and prevent complication" and which include:

17. Early Identification, with Accompanying Intervention and Stimulation, in Handicaps - such as deafness or Down's syndrome.

18. Effective Continuing Provision of Services to Families of Children with Disabilities - to promote progress of the child and integration of the family.

Crocker also includes those basic activities which bear on the ultimate potential for success in prevention efforts

including continuing research concerning the cause of developmental disabilities in order to provide an improved understanding of the contributing factors and continuing education of physicians and other professionals regarding the measures available to prevent developmental disabilities.

A number of states have identified prevention of developmental disabilities as a priority and have addressed this priority through various means. The State of Tennessee, for example, formed a task force in August of 1980 with the governor's wife, Honey Alexander, designated as the Chairperson. The task force determined that an effective prevention program must include, "... informing the general public of the causes and consequences of developmental disabilities." (3). Also, that each citizen has an important role in this effort and all of us must act responsibly to guard our own health and development of our children and other family members (3).

To again quote the Special Court Master, Lincoln Clark,

> Maine does not have a statewide coordinated program to prevent mental retardation. After a review of the programs of several other states, I recommend that Maine establish a program patterned on that of Tennessee, which established a 'Governor's Task Force on Mental Retardation' in 1980. Surveying the incidence of various causes of mental

> retardation in Tennessee, this Task Force made the startling prediction that 'By the year 2000, the incidence of mental retardation can be reduced by half.' This will not happen unless a well-planned program of prevention is agressively pursued.(4)

States such as North Carolina have placed a high priority upon the prevention of developmental disabilities. In North Carolina the legislature adopted a prevention policy, conducted a statewide conference involving 600 interagency people with the governor as the keynoter, conducted workshops on primary, secondary, and tertiary prevention actions, and created or maintained programs of screening, immunization, premature infant care, child neglect and abuse, early identification, intervention, evaluation and follow along, and professional continuing education. North Carolina also conducted an effort to locate every adolescent girl who had been treated for phenylketonuna for the purpose of involving them in a group program aimed at minimizing risks, established ten state funded tertiary level prenatal intensive care centers linked to a larger network of special maternity centers by a highly developed maternal and infant transport system, and established a high priority identification and tracking system to assure the receipt of adequate follow-up and interagency/program communications.

In the Report of the Select Panel for the Promotion of Child Health to the United States Congress and the Secretary of Health

and Human Services (5), 1981, it was identified that "There are three broad classes of services for which there is such a clear consensus regarding their effectiveness and their importance to good health that it should no longer be acceptable that an individual be denied access to them for any reason . . ." These services were identified as, " (1) Prenatal, delivery and postnatal care, (2) Comprehensive health care for children from birth through age 5 and (3) Family planning services."

The Illinois governor's planning council on developmental disabilities issued a report in 1979 entitled Prevention of Developmental Disabilities in Illinois: Options to Guide State Prevention Efforts (6). In that report which draws upon a similar report by the State of California (1977) it was discussed that "every successful action that reduces the incidence of developmental disabilities, regardless of cause, is a worthwhile step in the right direction."(7)

The report further outlines that,

> "Prevention is the responsibility of numerous agencies, organizations, health care providers, and (potential) mothers.
>
> Prevention efforts can address one cause independently of others, and
>
> existing individual efforts approach prevention from different conceptions about causal priorities,

causal interrelationships, and appropriateness of responsibility for prevention between society, medical professions, or individuals."

The State of Wisconsin began addressing the issue in a coordinated manner as early as 1975. Among the initiatives between 1975 and 1981 were the establishment of a task force to address the topic of prevention programming for physical and mental health which in turn recommended and implemented a statewide genetic services system in cooperation with the University of Wisconsin - Madison, increased employee assistance programs, the inclusion of prevention goals, objectives, and activities within State Plans for Mental Health, Alcohol, and Drug Abuse, and Developmental Disabilities Social Services, Aging, and Health, and the requirement that the various bureaus within state agencies assign a prevention function to specified staff members and requirements that the various community and county social services agencies/organizations contain objectives and plans for prevention. In 1977 a statewide conference was conducted which attempted to create an awareness related to health promotion and prevention services within programs. Conference participants became the nucleus for local coordinating councils, planning groups or prevention and wellness committees. In 1979 the Wisconsin legislature approved approximately $980,000 for a prevention and wellness grant program. A commission, which was established to provide advice and guidance, approved funding for 29 projects and subsequently drew upon the results of the pro-

jects to issue recommendations concerning public health, health promotion, funding for pilot projects, impact statements in legislative proposals, and employee health activities. (See attachment___).

In terms of this Maine report it is important that the term developmental disabilities be defined. The federal definition (see attachment ___) states that a developmental disability is a severe, chronic disability of a person which:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments

2. Is manifest before age 22

3. Is likely to continue indefinitely

4. Results in substantial functional limitations in three or more of the following areas of major life activity:

   a. self care
   b. receptive and expressive language
   c. learning
   d. mobility
   e. self-direction
   f. capacity for independent living or
   g. economic self-sufficiency

5. Reflects the need for a combination and sequence of special, interdisciplinary or genetic care, treatment, or other services which are:

a. of lifelong or extended duration

b. individually planned and coordinated

In summary, an individual is not necessarily developmentally disabled unless his/her condition reflects the full statement of the definition. This emphasis upon functional limitations results in placing priority upon prevention as well as service delivery and treatment and is dependent upon our understanding of the causes of the disability conditions.

Among the types of developmental disabilities are:

AUTISM: A syndrome characterized by severe disorders which begin in early childhood and interfere with learning, developmental rate and sequence, response to environmental events, communication, and interpersonal relationships.

CEREBRAL PALSY: Involves a group of dysfunctions characterized by difficulty in muscular control as well as sensory functions, with mobility affected in most cases in addition to speech and hand movements.

EPILEPSY: Involves a number of disorders of the nervous system, centered in the brain, which are characterized by sudden seizures, muscle convulsions, and partial or total loss of consiousness due to abnormal electrical discharges of brain cells.

MENTAL RETARDATION: Characterized by significantly subaverage intellectual functioning and deficits in adaptive beha-

vior. Mental retardation is a condition, not an illness or a disease.

OTHER NEUROLOGICAL IMPAIRMENTS: Including a group of higher brain dysfunctions, determined before the completion of the nervous system development, that substantially impact upon the complete, usual, and adaptive use of maturation of language cognition, memory, attention, fine motor function, and/or organically determined social behavior, and other nervous system or neuro-muscular disorders with similar deficits in adaptive behavior.

Related to the interests of this report are those concerned with infant mortality which refers to the death of infants in their first year of life and including infants who die during the neonatal period and neonatal mortality which refers to the death of infants between birth and 28 days.

Prevention has gained wide support among the public, public agency, and program planners/providers. This wide support can easily be countered by the reduction in federal support and the increasing competition for available money. It is important, thus, that providers work together to develop the most effective prevention plan possible.

One of the dangers with the launching of a statewide prevention effort is to segregate the emphasis among strategies in a manner that only supports primary versus secondary and tertiary

efforts, and to place the varying parties involved in competition for the limited resources, this will reduce the coordinated efforts required to use resources most effectively and will reduce the overall effect on prevention of developmental disabilities. The Illinois and California reports mention that prevention efforts are sometimes difficult to promote "since the effects are not immediately visable and are often justified only on the basis of statistical evidence.

The benefits to the individuals afflicted and their families is fairly apparent. To reduce the causation of individuals not being able to conduct their lives in a normalized and productive manner and to reduce the heartbreak and various negative impacts upon the lives of the family members is a just reason for expanding efforts which will reduce developmental disabilities. Beyond the humane goals there are those concerned with cost effectiveness. The cost savings related to prevention must be detected because the cost of prevention is immediate while the benefits which involve the avoidance of the cost of lifetime care are in the longer range future.

In Lincoln Clark's The Martti Wuori Case - Report to the Court he states,

> No price can be put on the anguish of parents of a mentally retarded child, especially when mental retardation could have been prevented. The public is generally unaware of the cost

> of neglect. When a child born in Maine is so retarded that he/she requires intensive, life-long care and treatment, the cost for an average life span of 72 years at present estimates of $36,000 per year, is $2,592,000. Any program that prevents even one case of mental retardation is worthwhile.(8)

In the Illinois report of Conley's study, The Economics of Mental Retardation (1973) is referenced(9). Conley considers the benefits of prevention for the average individual in terms of "total productivity gain" in which he includes: estimated lifetime earnings gained if an individual could work at full capacity, the value of homemaker services as determined by what could be earned if the homemaker was fully able to perform his or her duties, savings in institutional costs, and savings in income maintenance costs. Conley indicates that the total productivity gained is approximately two to three times the amount of savings in institutional costs for the severely retarded. Considering that the costs of institutional care within Maine can range from $30,000 and upward per year, and that generally these costs are based upon the direct custodial and programming aspects without consideration for the varying indirect costs incurred, the cost benefits can be substantial to the State of Maine.

In a concept paper entitled Would the Federal Government Make a Profit by Doubling the Budget of the Special Supplemental

Food Program for Women, Infants, and Children (WIC) for Pregnancy?, prepared by Erik Jansson, 1983 ( ) a study is referenced ( ) which documents an interrelationship of the WIC program for pregnancy with medical expenses of affected families and the reduction of low birth weight which can have a direct bearing upon the rates of handicaps and birth defects in children is discussed. Jansson states,

> In a study of Massachusetts births, their study showed clearly that for every $1.00 invested in the WIC pregnancy food supplements, a reduction of $3.00 in medical expenses for the affected families could be expected.

He further states,

> Putting this into business terminology, WIC has a 200 percent profit margin. (A $900 million investment generates $2.7 billion)( )

In an accompanying paper Total Costs not Including Loss of Economic Productivity, prepared by Jansson, some educational costs of birth defects are discussed. He references New York City in his statement,

> In the 1979-80 budget year, $409 million, including capital costs, was spent on special education or $7,958 per student. For comparison, New York spent $2,853 per student for all nonhandicapped

> youth (elementary, junior high, and high school). In short the cost of educating a handicapped child is 180 percent greater than educating a normal child.( )

The reduction of handicapped conditions in children can certainly have an impact upon the eventual reduction of special education funds. To further quote Jansson,

> It is fair to say that the extent that school districts do not provide special education to compensate for handicapped situations of children, that will be the extent of reduction of economic productivity costs of 6 or more percent of the population. It is also fair to say that the loss of economic productivity cost will exceed that of any annual schooling costs.

There are various other studies which have been conducted which address the issue of cost benefits such as GAO's Preventing Mental Retardation - More Can Be Done (1977)(10), the Center for Disease Control's cost benefit analysis on genetic disease programs Mental Retardation, Birth Defects and Genetic Disease Control Programs: A Cost Benefit Analysis(11), and others.

It is apparent that there are many cost benefits to prevention although the State of Maine may want to conduct more defini-

tive studies and cost benefit analyses as a part of its prevention process.

This study was funded through a contract from the Planning Council on Maine Developmental Disabilities in April of 1983. In order to begin the process of implementing a statewide, coordinated effort to address the prevention of developmental disabilities the grant was provided to Medical Care Development, Inc., a nonprofit research and developmental organization in Augusta, Maine. The project proposal is entitled Planning Project for A Statewide Program for Prevention of Developmental Disabilities.

The project goals are:

Goal I: To determine the present state of the art concerning prevention of Developmental Disabilities which can be used as a reference document for planning within Maine.

Goal II: To determine present prevention strategies, programs, and resources within the State of Maine; define the scope of coverage as related to geography, populations, and subcategories of developmental disabilities and mental retardation; determine barriers to present access or to expanding services; and develop priorities for new or expanded prevention programs.

Goal III: To determine the extent to which the prevalence of developmental disabilities within Maine can be determined and to recommend approaches for future data gathering and analysis which can provide an accurate measure of the effectiveness of prevention activities.

Goal IV: To define those representatives of the various agencies, professions, and professional societies who should be involved in prevention with special emphasis upon medical/health professionals.

The product of this effort is a summary of the findings with conclusions and recommendations which can assist the Developmental Disabilities Council and other state agencies in setting priorities and initiating a statewide effort for the prevention of developmental disabilities. The project has been guided by a steering committee of knowledgeable professionals and parents. Several physicians have also assisted on a special subcommittee of this group. (Attachment ___). A large number of representatives of public agencies and higher education professionals, early intervention professionals, health care prevention professionals, and parents have assisted through the personal and telephone interviews, written surveys, and informal discussions. Thus, this planning effort has in many ways started the process of coordination of developmental disabilities prevention services as well as defined the current status of prevention efforts in Maine.

Current literature related the prevention of developmental disabilities has been reviewed in order to provide basic information about present prevention strategies nationally, to identify information most relevant to the State of Maine's efforts, to provide a scientific justification for prevention strategies that might be persued in Maine.

The result of these efforts is a report that is indicated to provide the Maine Planning and Advisory Council on Developmental Disabilities with a "beginning" to what hopefully will be a long-range effort within the State of Maine to reduce the prevalence of developmental disabilities and the accompanying heartbreak and stress to families and costs to the state.

Recommendation 5:

Additional funding should be allocated to the Women, Infants, and Children (WIC) program so that additional mothers and children could receive nutritional food supplements and preventive health education through this program that has been proven effective.

Recommendation 6:

Medicaid coverage should be extended by the state to low income families and pregnant females to assure adequate access to preventive prenatal and newborn services for this high risk population. Pending federal legislation would make such coverage a part of the title 19 program which would greatly reduce the cost for the State of Maine. The state should agressively support this legislation through the National Governor's Council and the Maine Congressional Delegation.

Recommendation 7:

The Department of Education should advocate for the adoption by the local school departments of comprehensive health education, family life education, nutrition education, programs which cover such topics as fetal alcohol, smoking, and others related to the prevention of developmental disabilities.

Recommendation 8:

The knowledge and awareness of the general public concerning causes, consequences, and means of preventing developmental disabilities should be raised. The print and electronic media should be used as a vehicle for information and education. Methods should include:

1. A continued and expanded use of public service announcements used by the Office of Developmental Disabilities are appropriate, but there may be limitations concerning when such announcements are viewed and the extent of the educational content.

2. At least one "at risk" population and the related causation of developmental disabilities be targeted for electronic media advertising. This pilot effort should be professionally prepared with the advise of those involved in marketing who are able to identify appropriate viewing hours and the content of the presentation related to the target population.

## SUMMARY OF RECOMMENDATIONS

Recommendation 1:

The Developmental Disabilities Council should cooperate with Department of Human Services and providers to assure early prenatal care and education for all pregnant women regardless of socioeconomic circumstances. The Department of Human Services has funded a project at Downeast Health Services which provides prenatal care for women in Washington and Hancock counties, and women who are Medicaid recipients and already have a child also have access to prenatal care paid for by Medicaid. Department of Human Services should review access to care for first time mothers through Medicaid and for all women through such agencies as Public Health Nursing or other appropriate programs.

Recommendation 2:

A standard educational program should be developed for use by hospital nurseries for education of mothers about care of a new baby. These materials should compliment information presented in childbirth education classes and should be a reimbursable educational service for hospitals. Training should be provided to educators/newborn nurses to prepare them to present effective education for mothers.

Recommendation 3:

It is recommended that the state initiate a broad-base information/education program concerning the effects of maternal alcohol consumption upon the unborn child. This could be implemented through the use and coordination of existing state programs of the Department of Educational and Cultural Services and the physician education programs of the Department of Human Services.

Recommendation 4:

Support groups for pregnant females should be established throughout the state to assist them to pursue behavior that will minimize the risk associated with the pregnancy.

Recommendation 9:

Continuing medical education programs for physicians, nurses, and other health workers should be conducted on a regional and local basis. This program could incorporate criteria for referral, methods for risking pregnancies, newborn resuscitation, prenatal and newborn testing, genetics, and use of community support and educational services.

Recommendation 10:

Increase the use of genetic screening services in the state, such as AFP testing, through education of physicians and all pregnant women and by establishing comprehensive standards for screening.

Recommendation 11:

Involve Maine's Health Science Education Programs in the efforts to prevent developmental disabilities. These academic training programs include nursing, premedical education, human services, and health education as well as research and public service programs. Each program should include appropriate curriculum material related to preventing developmental disabilities.

Among the suggestions is to request that the schools appoint an academic task force to work with the Developmental Disabilities Council to review all aspects of the present academic programs which could incorporate the theory of developmental disabilities prevention. The members of this task force could then see that developmental disabilities prevention is indeed incorporated into the different curricula.

Recommendation 12:

Hospital transition programs should exist in all Maine hospitals in conjunction with discharge of a high-risk or at-risk newborn. The discharge plan should identify and include a plan of action which is supportive of well-child care. These activities might include social services, medical care, nutrition education if pertinent, and family counseling.

Recommendation 13:

That there be an emphasis upon the availability of clinical mental health services to families of clients with developmental disabilities and that the mental health workers be included in educational programs as they relate to developmental disabilities.

Recommendation 14:

A comprehensive plan for services for children from birth to three years old should exist. This plan should include identification, evaluation, and referral services for all children when it is suspected that they be at risk due to biological established or environmental factors.

Recommendation 15:

Support the expansion of Preschool Projects to improve early intervention services which can reduce the long term effect of developmental delay or disability.

Recommendation 16:

The Developmental Disabilities Council should support the efforts of statewide child abuse groups who see prevention as a key focus of public education. These include both private and public efforts such as the Department of Human Services project of parenting classes in Norway, Maine.

Recommendation 17:

The schedule of payment for services for pregnant females who are identified as high risk should be modified to encourage the delivery of services including counseling, education, and more frequent monitoring which could reduce the risk of giving birth to a developmentally disabled baby.

Recommendation 18:

Develop a system of communications/distribution of available resources and printed literature on such topics as maternal education, fetal alcohol, juvenile diabetes, genetic counseling, child abuse, and other topics related to prevention to physician's offices and other primary prevention locations.

Recommendation 19:

The State of Maine should actively support federal legislation to fund efforts to prevent developmental disabilities. Such legislation should include some of the elements of the "Birth Defect, Reproductive Health, and Health of Young Children Policy Act of 1983". Federal legislation should be supportive of the prevention efforts which are established as a priority for Maine.

Recommendation 20:

It is recommended that the revised birth certificate reporting form in combination with the hospital discharge data system be utilized to identify the prevalence of developmental disability among live births in Maine and identify those aspects of the pregnancy or genetic background which might be related to the disability.

Recommendation 21:

One or more regional coordination models should be established for community-based coordination of prevention related services. This could involve the appointment of a regional prevention coordinator as a member of an appropriate organization or agency. It is suggested that such a project be developed in a community where a preschool coordination project exists. The model used within Illinois might be an appropriate vehicle to be used within a pilot region.

Program activities must be based on local needs and could include a wide range of issues. Often persons in rural areas experience problems in transportation to local services such as regular prenatal or physician care, support groups, and WIC activities. Physicians in rural areas also note the problems inherent in transfer of infants in need of special care to Level II and III nurseries. Such specific needs as these may be addressed as well as various educational and public information projects and preventive health care services through closer cooperation among the various provider agencies.

Recommendation 22:

Establish a statewide steering committee to plan and coordinate the development of a system of medical, social, and educational services for prevention of developmental disabilities in Maine. This should be a select committee appointed by Governor Brennan with members who have broad knowledge and experiences in all aspects of Maine's medical, mental health, educational, and social service programs and who can effect the coordination of developmental disabilities prevention with other major health initiatives such as child health and environmental health.

Recommendation 23:

Establish or designate an administrative unit to provide support and administrative services to the steering committee in its efforts to implement the prevention of developmental disabilities as a State of Maine priority and to provide the subsequent coordination of effort necessary.

Recommendation 24:

Commensurate with the implementation of the various new efforts to prevent developmental disabilities in Maine, the Developmental Disabilities Council should establish an ongoing evaluation program to measure the impact of various interventions and to document the extent of activity that has occurred to produce a positive result.

The time to design the evaluation process is at the beginning of a program and should be done in concert with the design of goals, objectives, and activities. It is proposed that one of the grants of the Developmental Disabilities Council should be for an independant design of an evaluation process for the State of Maine's coordinated effort to prevent developmental disabilities.

Recommendation 25:

The Commissioners of Human Services, Mental Halth and Mental Retardation, and Educational and Cultural Services establish a policy requring that appropriate units and contracted agencies within their agencies, based upon the receipt of information and/or orientation programs, develop an internal plan for the prevention of developmental disabilities related to their individual roles and that such plan be required to be updated on an annual basis.

## EXISTING PROGRAMS TO PREVENT DEVELOPMENTAL DISABILITIES IN MAINE

DEFINITION:

The Maine Planning Council for Developmental Disabilities in its three-year state plan (1981-1983) uses the federally accepted definition of developmental disabilities as stated in the REHABILITATION, COMPREHENSIVE SERVICES, AND DEVELOPMENTAL DISABILITIES AMENDMENTS of 1978 upon which to base its planning activities. The state accepts the basic precepts of the definition but expands them, relating them to Maine's own problems. Briefly the nationally recognized definition of developmental disabilities is as follows:

> ...a severe, chronic disability of a person which--
>
> (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
>
> (B) is manifested before the person attains age twenty-two;
>
> (C) is likely to continue indefinitely;
>
> (D) results in substantial functional limitations in three or more of the following areas of major life activity:

(i) self-care

(ii) receptive and expressive language

(iii) learning

(iv) mobility

(v) self-direction

(vi) capacity for independent living, and

(vii) economic self-sufficiency, and

(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are individually planned and coordinated.

It should be noted that this statement marks an important change from previous developmental disabilities programs which focused on particular disorders or diseases (such as mental retardation, cerebral palsy, or autism). The 1978 definition focuses on the level of functional impairment rather than categorical cause of the impairment so that limitation in several major life activities, due to any number of physically or mentally handicapping conditions, is the basis for program participation (DD Council, 1980).

## PREVALENCE OF DEVELOPMENTAL DISABILITIES

Prevalence and incidence data on the developmental disabilities population in Maine are difficult to obtain, due in part to the lack of uniform centralized data collection. The Council, for planning purposes, has estimated the current developmentally disabled population in Maine based on a formula designed by EMC Institute for a national study. These estimates give a very general picture of the state's developmentally disabled population, but may not accurately reflect the real geographic distribution of the population, and other characteristics which are important for planning preventive interventions. However, taking these limitations into consideration, the state has been able to estimate the developmental disabilities population by county and by age groups--both of which are essential for program planning. The total estimated projected developmental disabilities population in Maine for FY 1983 is 18,055; 1,778 being preschool age (0-2 years) and 5,649 being school age (3-17 years) (Council, 1980).

For purposes of planning prevention programs, however, the incidence of developmental disabilities--new cases among the live birth population--may be a more appropriate measure. From the literature, the following group of data representing the rate of prevalence of various diseases among live born infants have been compiled.

| | |
|---|---|
| Marfan's Syndrome | 1 in 20,000* |
| Phenylketonuria | 1 in 12,000* |
| Galactosemia | 1 in 57,000* |
| Homocystenuria | 1 in 200,000* |
| Hemophilia | 1 in 10,000* |
| Down's Syndrome | 1 in 1,000* |
| Hypothyroidism | 1 in 5,000-10,000** |
| Maple Syrup Urine Disease | 1 in 170,000*** |
| Neural Tube Defects | 1-2 in 1,000**** |

*CECIL TEXTBOOK OF MEDICINE. 16th ed. ed. by J.B. Wyngaarden and L.H. Smith, Saunders, 1982.

**Eggertsen p. 33

***W. A. Miller, NEWBORN GENETIC SCREENING. No date.

****ACOG News Release, June 17, 1983

According to statistics kept by the Newborn Screening Program within the Bureau of Health, rates in Maine for 1981 and 1982 of five inborn errors of metabolism which cause mental retardation are as follows:

| | 1981 | 1982 |
|---|---|---|
| Number infants screened | 16,929 | 16,572 |
| Hypothyroidism | 1 in 5,643 (3 cases) | 1 in 4,143 (4) |
| PKU | 1 in 5,643 (3) | 1 in 16,572 (1) |
| Homocystenuria | 0 (0) | 1 in 16,572 (1) |
| Galactosemia | 1 in 16,929 (1) | 1 in 16,572 (1) |
| Maple Syrup Urine Disease | 0 (0) | 0 (0) |

However, two years of data for disorders which show up so infrequently in the population are not sufficient to determine firm annual incidence rates in a state with such a small annual birth population as Maine's.

Other sources of information include the vital statistics report from the Maine Division of Research and Vital Records, and data from the Maine Fetal Risk Project. According to the annual Maine vital statistics report, out of over 16,000 live births in 1980, 235 were reported as being affected by some type of congenital anomaly. This is 1.4% of the liveborn population or 1 in 70. However, there has been a lack of uniform reporting on birth certificates by physicians and this figure may not be truly representative. In some cases anomalies which would not match the federal definition of a developmental disability as being one which restricts at least three major life activities may be reported; yet at the same time some physicians may not

report some anomalies, or they might not be evident at the time of birth. Coburn, Bennert, and Bennert (1982) in the final report on the Maine Fetal Risk Project, state that 12.7% (1 in approximately 8) of the live births studied in a one and a half year period had some kind of morbidity outcome, not necessarily a developmental disability including low birth weight, transfer to neonatal intensive care center, a five minute Apgar score of less than seven, and retention of newborn in hospital after mother's discharge. pp. 67). Both the vital statistics report and the Coburn study include information on newborns who are affected by conditions which may or may not be defined as developmental disabilities, but they may be used as indicators in estimating the prevalence of disabilities and diseases among the live born population. The Coburn study especially links morbidity outcome as well as fetal and neonatal mortality with various socioeconomic maternal characteristics--an important consideration in designing developmental disability prevention activities.

## EXISTING PREVENTION ORIENTED PROGRAMS AND SERVICES

As part of the information gathering process of this project, staff spoke with representatives from the Bureau of Health, Department of Mental Health and Mental Retardation, and DECS regarding the various activities which they plan, fund, or administrate. In Maine there are numerous programs for prevention and early intervention of developmental disabilities, both public and private. The Bureau of Health, DHS, has been particularly active in

prevention, both in newborn screening and in social and health education.

One of the programs within the Bureau which immediately addresses prevention issues is the Newborn Screening Program, mandated by a 1965 statute of the State of Maine, which tests all newborns for five inborn errors of metabolism. The program is currently funded through federal money and is part of the New England Regional Screening Program. The Bureau provides screening kits to all hospitals and then sends all specimens to the Massachusetts State Laboratory. Parents are charged for the initial screening, but for follow-up tests the program pays for the kit. Records are kept at the program office and are filed manually. This program is an important source of information, and retrieval of information would be facilitated if files were computerized.

The state also funds various genetic screening programs in the state including activities at Eastern Maine Medical Center in Bangor (with Presque Isle and Machias satellites) the Foundation for Blood Research which has an active genetic education component and Maine Medical Center. As part of their committment to genetics activities, the state also provides education to high school biology teachers so they might inform their students of genetics issues, and some provider education which is aimed also at developing screening tools (the Maine Fetal Risk Project worked with physicians to test risk assessment as part of the prenatal record system).

The director of the state's genetic programs feels that the services now being offered are very good, but that the public must be made aware of the importance of screening and education, and that providers must learn to think in terms of prenatal genetic screening. As an example, AFP testing is solely the choice of the parent and physician, and only about 30-40% of the pregnancies in Maine are tested. AFP tests in this state are sent to the FBR for analysis. The FBR feels that AFD screening should be taken advantage of by a much larger number of pregnant females and that both provider and public education are the means for accomplishing this.

Many of the other programs within the Bureau of Health which impact upon developmental disabilities use public and health education as a mechanism in preventing childhood disorders. The state is active in childhood accident prevention, and works with hospitals and educators regarding infant car seats and poisons. They plan to address fire and falls in the near future. The Bureau has purchased 5-6,000 car seats which are now available for use in hospitals around the state; private groups such as churches also have car seat programs. They also provide education and information packets regarding poisons to parents, hospitals, teachers, babysitters, and grandparents.

Environmentally-related programs include a small lead screening program in which the public health nurses are actively involved and programs addressing child abuse. This latter issue

is an important one in Maine. In 1981 alone there were 4,069 families assigned to caseworkers which had been referred to Child Protective Services. Of the 4,273 case studies which were completed in that same year, 56.5% of the initial referrals were found to be substantiated. The Bureau is focusing on education and support groups as a means to address the problem. They have funded a 12-month pilot parent outreach program in Norway, Maine, which was developed jointly with the local school system. It is a course aimed at the rural poor and includes both home visits and class time. Apparently, future funding may not be available for the program. A second year-long program now being planned will establish four parent support groups aimed also at the rural poor, especially those not already identified by Child Protective Services.

The Bureau's provider education activities include training courses for those who will be doing parent teaching, education for public health nurses who already do much family counseling, curriculum development for a component on child abuse in child-birth education programs (through Eastern Maine Medical Center), and education about high risk pregnancies and parenting skills made available to any Maine hospital through Maine Medical Center.

The Bureau of Health would like to see more training for providers to help them identify the signs of child abuse or neglect.

The Women's, Infants', and Children's program, already proven to be successful nationally (Jansson, 1983), provides nutritional supplements and education to mother and children in Maine. Administrated by the Bureau of Health, it is totally federally funded and is currently serving a caseload of approximately 14,000 each month. Referrals come to WIC through Public Health Nursing, physicians, schools, social services, and hospitals. The program also does some outreach, such as mailing information with AFDC checks. In FY 1982, the program in Maine received $5.3 million from the U.S. Department of Agriculture: 77% was used for food, and the remaining amount was used for nutrition education and administrative costs. All of the agencies which contract with the state to provide program services provide nutrition education either in class or group situations or via individual counseling. The Bureau does some evaluation to assure compliance with federal policies and also performs an annual participant survey. Some data on the program has been computerized, though no analysis had been performed at the time this information was collected. However, this program is a potentially rich source for data on children and pregnant women at risk due to socioeconomic status. Currently the Bureau is aware that quality of nutrition education is uneven across the state and would like to work with the WIC agencies to provide uniform high level counseling. The Commissioner of Human Services has indicated that the WIC program could be greatly expanded if more federal funding were available.

One of the basic tenets of prevention of developmental disabilities is the prevention of infectious diseases. The Bureau's immunization program not only distributes vaccine for mumps, measles, and rubella, but also for polio, diptheria, pertussis, and tetanus. The state requires that children are immunized by the time they enter school or at school entry. Approximately 96% of Maine children are currently being immunized. The program also performs an annual assessment of school entrants who are immunized and distributes some educational materials for both the public and health care providers. Due to funding limitations there seems to be some question as to whether free vaccine will continue to be available, which means some children might not be immunized. However, currently the program is comprehensive and works effectively to prevent occurrence of infectious diseases.

The Maternal and Infant Care activities within the Bureau are for the most part treatment oriented, though they have been involved with prevention via prenatal care. The Maternal and Infant Care Project provides prenatal care for women in the Washington and Hancock County area, through Downeast Health Services. In the past as many as 50% of the women in Washington County were enrolled, and physicians still refer many of their patients. Statewide, as much as 80% of public health nursing activities are related to maternal and child health, and much of the work that is accomplished is prevention-oriented whether through well-baby clinics or counseling or families.

When asked what problems might be encountered in continuing to provide services at the Bureau of Health, staff most often mentioned lack of adequate funding to coordinate, expand, or extend pilot programs or programs now available in only certain regions of the state, resulting in uneven coverage, both geographically and qualitatively.

Some of the activities of the Department of Educational and Cultural Services, while chiefly oriented toward identification of and intervention for developmentally disabled children, do relate to prevention. The school system in Lisbon, for example, with funding from both DHS and DECS has designed a school-based program which includes, among other services, preventive programs such as education and information for both teaching and administrative personnel and the public. The Department was instrumental in developing health education curricula for high schools and also has an active Division of Alcohol and Drug Education.

Areas addressed in interviews with several service providers outside the state government focused on prenatal care, maternal education, screening, and adolescent pregnancy. Approximately 1% of live births in Maine each year occur outside of the hospital. Some of these births are attended either by lay midwives or one of three Certified Nurse Midwives who attend home births in the state. A CNM who does home births and who is active in establishing an association of lay and nurse midwives (Midwives

of Maine) was interviewed. She felt that both lay and nurse midwives are conscientious about counseling their clients regarding smoking, alcohol, and nutrition. Nurse midwives routinely do blood tests for all clients, including rubella titre, Rh, and VDRL. Most lay midwives require their clients to visit a physician's office at least twice during the pregnancy, and that is where blood tests are performed. One of the first issues which will be addressed by the new MOM association is the development of standards of care, including laboratory testing.

Among the nurse midwives counseling regarding AFP blood serum tests and amniocentesis is available on an individual basis. Routinely they do not counsel for amniocentesis based on the mother's age, but only if there is a history of prematurity, anomalies, or other problems in the family. Like many physicians, the nurse midwives will not consider amniocentesis unless the mother is willing to abort. It is felt that the procedure presents too great a risk and can be to psychologically damaging to perform if the woman will not act on the results anyway.

The family planning clinics in the state are an important link in prevention services as they reach a large number of teenage women before they become pregnant. Besides family planning counseling and services, the service providers and the counselors discuss smoking, alcohol, and nutrition with their clients. The clinics make a wide variety of posters and pamphlets on these and other subjects available in their waiting

rooms. Family planning sites offer low-cost nonthreatening environments for young women and should not be overlooked in statewide or regional prevention planning.

In 1981, 14% (2,337) of all births in Maine were to adolescent mothers, and almost 32% (781) of those births were to teenagers 17 years of age or younger. The Statewide Service Providers' Coalition on Adolescent Pregnancy addresses some of the problems associated with adolescent pregnancy. The Coalition is a network of service providers which acts as a conduit for federal and state funds which support demonstration projects for at-risk, pregnant, and parenting teenagers. Currently the Coalition receives MCH block grant funding from the Department of Human Services for nine projects throughout the state. Each project is somewhat different, but generally the services provided include prenatal and childbirth education classes, parenting classes, support groups, individual counseling, referral services, school programs, and infant stimulation. Though many of the services are aimed at pregnant or parenting teenagers, at-risk adolescents are also targeted. For all clients, the coalition tries to complete a two-year follow-up program which measures the health of mother and child, continuation of schooling for the mother, self-sufficiency of the mother, and repeat unplanned pregnancies.

## EARLY INTERVENTION SERVICES

Though early intervention programs are not the primary concern of this report, they must be considered in any developmental disabilities prevention planning because they do function as secondary prevention services. Early intervention and educational programs can serve to prevent further physical or mental limitation and deterioration in affected children, and may also serve to keep the family aware of their genetic history so that they might make informed decisions about further pregnancies.

A survey of the prevention/early intervention programs statewide was conducted in order to gather valuable input from these service providers regarding the ways that they contribute to the prevention of developmental disabilities. Our interests were to find out:

1. The types of developmental disabilities prevention being offered and by whom.

2. The obstacles to and recommendations for more comprehensive prevention services in Maine.

Approximately 36 provider agencies were surveyed with a response rate of 50%. The 18 respondents serve approximately 970 disabled clients. Except for geographic differences in obstacles to services such as the need for a better transportation system in rural areas, there were many similarities in the types of responses we received.

Few respondents claimed to provide prevention services. Most offer early intervention services or parent support services, and their responses reflect their involvement with already identified disabled children. The few prevention oriented services that were being offered were care for premature infants, and education regarding alcohol intake during pregnancy, child abuse and neglect, and nutrition.

Most respondents noted that their services to clients were not mandated; the few exceptions were mandated by the Bureau of Mental Retardation, the Mental Health Centers Act, etc.

The primary eligibility requirements for clients served by these respondents were the possibility of identified developmental delay, and parental approval or involvement. Some also required a physician referral.

Services were funded essentially by Medicaid, private insurance, and out-of-pocket by the client. Except for two providers who served only people with Cerebral Palsy or Downs Syndrome, all were interested in providing services to clients with any type of developmental delay or disability. All respondents served children ages 0-5, and three of those extended service into the teenage years.

A majority of providers stated that they evaluate the impact of their programs through various mechanisms such as client estimates, trends in numbers of participants or percentage of the

target population reached, number of referrals, time survey of clients and parents, and measurement of the child's progress using psychological or developmental tests.

When respondents were asked generally what obstacles they saw to the provision of services within their programs, their response was similar to the concerns expressed by those providers of prevention services already interviewed: Lack of funding, not enough physicians/provider participation in the program, and lack of coordination of services. Other obstacles identified were: Not enough physician referrals, lack of qualified personnel, not enough technical support for day-care staff, no unified client evaluation process, and lack of transportation.

Finally, these obstacles, together with the stated needs for services, prompted the following recommendations from the respondents.

Establish a clearinghouse for coordination of services and information concerning developmental disability problems for providers and families, resulting in a communications network to assure comprehensive coordinated services to clients. This sort of distribution of information would prompt better, more frequent referrals by physicians as well.

Parent groups recommend a stronger emphasis on peer support and resource groups for themselves which would provide

them with the encouragement to ask their primary care providers, especially physicians, appropriate questions. They expressed a great deal of concern that their physicians are lacking the knowledge, and sometimes motivation, to deal with their children adequately. Their feelings of overwhelming vulnerability at the time of detection of problems would be reduced by physician's assurance of knowledge and sensitivity to developmental disability problems.

Several respondents targeted as a priority the area of improvement of clinical mental health services to families of developmentally disabled children. They recommend a program that encourages families to learn to deal with their own needs as a family, incorporating the needs of their own "special child".

In the area of program funding, providers recommend a consistent, stable funding base so that a more concerted effort can be placed on programmatic issues as opposed to fiscal survival. In that light, they urge a look at better coverage for early intervention services by private insurance companies and, more specifically, improved Medicaid reimbursement for private physical therapists.

Respondents spoke often about the problems of service provision in rural areas. Increased transportation services are recommended to make service programs and physician visits more

accessible. Also more funding should be directed to home stimulation programs and to the acquisition of mobile education units for these areas.

Service providers especially are concerned about the recruitment of physical therapists and occupational therapists to provide direct service and training in developmental disabilities.