

MAINE STATE LEGISLATURE

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REPORT TO THE 109th LEGISLATURE
JOINT STANDING COMMITTEE ON
HEALTH AND INSTITUTIONAL SERVICES

BY

THE BUREAU OF MENTAL RETARDATION
DEPARTMENT OF MENTAL HEALTH AND CORRECTIONS

JANUARY 15, 1979

As required by Chapter 464, Title 34, MRSA as enacted by the 108th Legislature, the following report is submitted for consideration by the Joint Standing Committee on Health and Institutional Services.

Inasmuch as this report is required by the enactment of Maine Statute which guarantees in law the rights of the mentally retarded citizens of Maine, the report will summarize and highlight service delivery aspects of care for the mentally retarded and will focus on those aspects of care which most seriously impact the rights of the mentally retarded in Maine.

1) Key Legislative Developments During the Past 18 Months

Simultaneous with the enactment of a Bill of Rights for the Mentally Retarded in July of 1977, a companion piece of legislation (Chapter 502, Title 34, M.R.S.A.) was enacted in July of the same year which has had profound impact on the lives of the mentally retarded. Chapter 502, for the first time in Maine history defined the obligation of the State through the Bureau of Mental Retardation to provide community-based services within the State. The legislation defined the organization of State regional offices,

area-wide Resource Centers, and imposed more-defined statutory limitations for admission and continued resident status in the State's primary residential centers for the retarded. Pineland Center, located at Pownal, and the Elizabeth Levinson Center, located in Bangor, were principally affected by the statutory limits imposed by the legislation.

Both pieces of legislation contain the key provisions found within the plan of action outlined by the Bureau of Mental Retardation in January, 1977 entitled COMPREHENSIVE MENTAL RETARDATION PLAN: DIRECTION, ACTION, SERVICES. That plan remains as the basis of philosophy and direction for services to the mentally retarded in Maine.

The Comprehensive Plan developed in 1977 was intended both to shape the philosophy and direction of services to the mentally retarded as well as to respond to the myriad of issues and deficiencies which had resulted in the filing of a Right to Treatment Suit against the State of Maine in United States District Court in July of 1975.

From July 1977 through July of 1978 extensive negotiations were carried out between representatives of the State including the direct involvement of the Commissioner of the Department of Mental Health and Corrections and lawyers from the Office of the Attorney General with lawyers for the Plaintiffs in this class action suit. With the support of the Attorney General, the Governor, and the Legislature, a Consent Judgment, which are attached with this report, are detailed, complex, ambitious, and professionally sound. The provisions within these Appendices have the force of Federal Law and are binding on the State of Maine. Coupled with the "Bill of Rights," (Chapter 464) and the "Services Bill for the Mentally Retarded" (Chapter 502) they constitute the sub-

stantive basis for the plan of care and services for Maine's mentally retarded population.

2) Plan for Provision of Services 1979-80

As outlined in the Pineland/Community Consent Decree, the Bill of Rights for the Mentally Retarded, and the Act to Provide Services to the Mentally Retarded the Department through the Bureau of Mental Retardation will continue to provide services through but not limited to the following programs:

- A) Pineland Center
- B) Elizabeth Levinson Center
- C) Aroostook Residential Center
- D) Six Regional Offices responsible for Specific Regions
- E) Two State-operated Resource Centers
- F) Infant Development Center
- G) Developmental Disabilities Planning Council

The above are State-operated programs and services. In addition, the Bureau of Mental Retardation has service and financial obligations to more than forty incorporated, community-based programs serving the mentally retarded throughout Maine which provide developmental activity and vocational programs for adult retarded persons in the State, more than two hundred residential programs for the retarded including group homes, boarding homes, and nursing homes.

Consistent with expressed Maine Legislative intent, pertinent Federal legislation, and the Pineland/Community Consent Decree a continued policy and programmatic focus will be on improving the quantity, quality and geographical distribution of services for the mentally retarded and their families. Accordingly, budgetary support for the development and maintenance of such programs will be introduced in the budget request submitted by the Governor to the Legislature.

Additional areas for which specific action by the 109th Legislature will be requested by the Bureau of Mental Retardation including the following:

A) Revision of Maine Statute governing the sterilization of mentally retarded persons. The Bureau of Mental Retardation is concerned that the current Maine statute is inadequate to provide full protection of the legal and human rights of the mentally retarded in terms of sterilization.

B) Revision and simplification of the Statutes requiring Court Certification of residents of Pineland Center and the Elizabeth Levinson Center.

C) Revision of Special Education Laws particularly as existing laws create barriers to the provision of education services to currently and formerly institutionalized school-age residents of State institutions for the mentally retarded.

D) Specific legislative clarification authorizing the Bureau of Mental Retardation to operate under State auspices a residential/vocational program in the Town of Freeport as authorized by the 108th Legislature.

E) Specific legislative authorization for the Department of Mental Health and Corrections and the Bureau of Mental Retardation to lease State-owned property and buildings to non-profit community groups which provide services for the benefit of clients of the Bureau and Department.

In addition to the above areas which require Statutory action, it is the belief of the Bureau of Mental Retardation that the State of Maine, through the Executive branch of government needs to address a number of areas through administrative policy changes which would considerably enhance the effectiveness and efficiency of service delivery to Maine's mentally retarded population.

In this latter regard, a number of administrative changes have been suggested, initiated or are under current consideration by the respective branches of State government which would improve the effectiveness of services to mentally retarded persons.

Particularly as it relates to inter-departmental cooperation in the coordination of services to the mentally retarded, significant gains have been made in the following areas in the last year:

A) Group Homes for the Mentally Retarded - While the Bureau of Mental Retardation has been involved in stimulating the development of small group homes for the mentally retarded there has been increasing recognition of the need to provide flexibility in the State's Reimbursement Principles to these homes which allows increased staffing where it can be demonstrated that the behavioral characteristics of the resident population are such that additional staff and State support are needed. The Bureau of Social Welfare has been sensitive to this need and has accordingly revised its Principles of Reimbursement to accommodate the need.

B) Fund Allocation of Title XX Social Security Support for Community Programs for the Mentally Retarded.

Until fiscal year 1977 in spite of the fact that there were hundreds of unserved mentally retarded persons within the State, several hundreds of thousands of Title XX funds were lapsing to the Federal government due to ineffective monitoring of fund allocation. With the cooperation of the Bureau of Resource Development a jointly-shared process of allocation of Title XX funds for mental retardation services has been put into effect with the result that all such earmarked funds are being utilized to the fullest with no loss of Federal fund support.

C) Improving the Availability of Sheltered Workshop Programs for the Mentally Retarded.

The provision of an adequate supply of sheltered workshop opportunities for the mentally retarded has been a long standing concern of persons responsible for the care and treatment of the mentally retarded within the State. Shortage of such sheltered workshop opportunities has been due to lack of awareness of the capability of the mentally retarded, complex and at times contradictory Federal regulations, accreditation requirements which place smaller programs at a disadvantage and limited State support for such programs. With the involvement and cooperation of the Bureau of Rehabilitation recent strides have been accomplished which has resulted in a noticeable increase in such sheltered workshop programs. It is anticipated that during 1979-80 additional workshop opportunities will be made available for the mentally retarded.

D) Improving the Array of Federally Supported Housing Opportunities for the Mentally Retarded.

In spite of the fact that for a number of years a myriad of Federal Housing programs for the handicapped have existed, the mere existence of such Federal Programs has nonetheless not resulted in benefiting Maine's mentally retarded and their families. After collaboration with and the signing of a joint agreement with the Maine State Housing Authority, a number of housing demonstration projects are planned for 1979 which will result in ongoing Federal support for housing for Maine's mentally retarded population.

E) Improving the Quality of Developmental and Vocational Programs for the Mentally Retarded.

With the mutual involvement of representatives of the Bureau of Rehabilitation and of the Bureau of Resource Development along with representatives of the Bureau of Mental Retardation and private agency representatives, joint standards are being developed for service programs which serve retarded persons and which are funded by either or all of the above listed State agencies. This will both make it easier for local groups who deal with multiple State agencies as well as provide for better assurance of equal quality services regardless of where one lives within the State.

F) Improving Individualized Case Services to the Clients of the Bureau of Mental Retardation.

Chapter 502, Title 34 M.R.S.A. defines specifics in the procedures and elements required for the development of Individualized Program Plans for clients of the Bureau of Mental Retardation. After a full year of experience with this mechanism for meeting the service needs of BMR clients, an extensive review is currently underway which will involve clients themselves, parents, private agencies and State personnel who will ultimately make recommended changes for improving and simplifying the process.

G) Improved Training Opportunities for Personnel Working with the Mentally Retarded.

As a result of the support from the Department of Human Services Staff Development Unit and the University of Maine's Human Services Development Institute, improved training will be available during 1979 for staff of public and private agencies serving our clients at regional locations across the State.

3) Pineland Center Plan for Provision of Services 1979-80

Implementing the requirements of the Pineland/community Consent Decree has been and continues to be the major goal, focus, and plan for activities of Pineland Center staff. P.L. 502 and P.L. 464 mandates

were incorporated into Consent Decree standards during the negotiation process to ensure consistency in policy and program efforts.

The degree to which the facility successfully accomplishes its mission has a direct relationship to the success of all other components of the Bureau system. Budgetary support of the facility must be coupled with budgetary support of community programs and services to ensure the timely community placement of residents who do not require the restrictive treatment setting of the institution. Concurrently, the ability of the facility to respond to the admission requests of mentally retarded persons currently in the community who require institutional care and services dictates a total system approach to ensure prompt and appropriate client flow.

All legislation requested by the Bureau has, therefore, direct or indirect impact upon Pineland Center. Negotiations and agreements with other agencies in state government have similar implications to the facility and obviously the budget request to the Legislature will have most direct effects on Pineland Center.

4) Issues Which Require Attention by the Legislature

A) Use of Medicaid (Title XIX) Funds for Services to the Mentally Retarded.

In 1974 the U.S. Congress and the Department of Health, Education and Welfare, in response to both parental and professional testimony which underscored the need for more adequate treatment of the mentally retarded patients residing in the nation's intermediate care facilities (ICF's), established a special category of care within the Medicaid program known as ICF-MR.

The expressed purpose of this category was, and remains, to provide for the active treatment needs of mentally retarded persons being cared

for within public institutions and specialized nursing homes for the mentally retarded. The promise of this program has been only partially realized within the State of Maine.

At Pineland Center fewer than forty per cent of the existing beds have been certified by the State as ICF-MR beds. It should be of the highest priority for the State of Maine to apply for full ICF-MR status for all beds at Pineland thereby creating medicaid support for what is currently supported by State tax dollars. The additional medicaid support would increase revenues to the State General Fund and to the Mental Retardation Improvement Fund by millions of dollars.

Furthermore, it is in the best interests of the State to investigate the potential for use of Medicaid funds to support small group homes, day treatment programs for the mentally retarded and potentially specialized foster care programs since these services are currently dependent on State funds with minimal Federal financial participation.

Over the next two years it is anticipated that approximately one hundred ICF-MR beds will be created in small (20 beds per) ICF-MR facilities distributed across the major population catchment areas of Maine. This should have significant impact on improving the quality and availability of care and treatment to the severe and profound range of mentally retarded persons.

B) Transportation Issues

In a State of 33,000 square miles with a population distribution such as Maine's, transportation is critical to the lives of the mentally retarded and their families.

The Bureau of Mental Retardation supports the need to involve significantly the Maine Department of Transportation in the design and operation of public and private non-profit transportation services for the handicapped. There are current, serious problems in assuring needed

transportation services to the retarded in the State, and in particular to those persons who require transportation each weekday in order to attend developmental activity or sheltered workshop centers.

No more pressing problem than transportation has been expressed in virtually all sections of the State, with hardships created for the handicapped since they must share an already strained regional transportation system for their needs.

C. Pre-school Services

Significant numbers of young, developmentally delayed children between the ages of birth and age five, for want of available professional and consistent stimulation and developmental assistance, are considerably less likely to benefit from later education and training because help was not provided during these critical pre-school years.

Limited public financial support is currently available for these programs and where such support is available frequently income-eligibility rules become barriers which prevent middle income parents from being in a position to avail themselves of needed support and services for their special children.

Therefore, the Bureau of Mental Retardation will be examining options with other State agencies and present groups in order to lessen or eliminate the income barriers which are resulting in the denial of services to the developmentally delayed of pre-school age. This is a particular problem in Title XX SSA supported Mental Retardation Services since it precludes services to families whose income is more than 80% of the State's median income.

D) Publicly Supported Educational Opportunities

Persons concerned with improving the educational training opportunities for mentally retarded persons, including State community workers have repeatedly noted the extremely small number of Maine's mentally retarded school-age population who benefit from the vocational education system. One of the major barriers to obtaining voc-ed training is the current Maine administrative requirement which requires students to complete Sophomore high school year before admission. There should be a systematic opportunity for the mentally retarded to access vocational education by a waiver of the academic requirements.

Conclusion

The above, coupled with the attached documents, constitute the plan for policy and program direction over this biennium.

Kevin W. Concannon
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