

MENTAL RETARDATION LEGISLATION IN NEW YORK STATE

*William T. Conklin**

“Our final diagnosis is complete, Mr. and Mrs. Jones; John suffers from a congenital form of mental retardation.”

Trauma is the best way to describe the emotions. The feelings are so profoundly mixed and arise with such rapidity that it is extremely difficult to rationalize them. The physician, despite all of his euphemisms and suggestions of hope, has confirmed what you suspected or already have known, silently – your child is retarded!

A flood of guilt, despair, shock and, perhaps, outrage that this should be happening may be the most immediate reaction. Future is gone; only the reality of the present is with the parent. Whatever the severity of the condition, initially, the impact on the parents is great and traumatic.

In their loneliness, however, parents of a retarded child are not really alone.

The American Medical Association has estimated that one-to-three percent of the population will be diagnosed as mentally retarded at some point during their lifetime. While retardation is usually diagnosed in early childhood and more severe forms are obvious at birth or shortly thereafter, an all too large number of mental retardation cases are often undetected until the child starts school or is a grade or two into the school system, because of the mild nature of the condition.

From two to six million Americans are statistically projected to have some form of mental retardation, as yet undiagnosed. It is estimated that six million have already been identified in the population. The retarded and their families number 24 million in the United States today. This group constitutes the largest constituency of any single handicapping condition.¹

The focus of this article will be on the mentally retarded in New York State: their problems, progress, and goals for change. The issues we examine represent the important developments in this area in the last three decades leading up to the present and outline some fresh hope for the future.²

*Deputy Majority Leader, The Senate, State of New York.

1. New York State Association for Retarded Children, *Report of Task Force on Mental Retardation*, at 1 (mimeo, 1974) [hereinafter cited as Task Force Report].

2. Throughout this article, the term “mental retardation” will predominate instead of “developmental disability.” Although the two terms are often meant to have essentially the same meaning, New York State law does not have a definition for “developmental disability,” as does Federal law (PL 94-103). To reflect New York State law, the term “mental retardation” has been utilized throughout this article.

Despite the reference to mental retardation in New York law, those afflicted by cerebral palsy, autism, brain injury and other neurological disorders—often known as “developmental disabilities”—are given entry into the state’s Department of Mental Hygiene programs because they can benefit from programs required for, or similar to, those for the mentally retarded.

Most medical authorities define "mental retardation" as sub-average intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior.³ Of the more than 250 known causes of retardation, including genetic causes (for instance, Down's syndrome), disease, environment, brain damage before or during birth, and injury, the affliction may also be accompanied by cerebral palsy, blindness, deafness, emotional illness, or any and all other illnesses which afflict the rest of society.

To the parents of a retarded child, the affliction is often perceived as particularly theirs and theirs alone. It has always been so in the past. Community or governmental assistance and, most of all, understanding have been long in coming and are still short in quality and availability.

THE RETARDED CAN ACHIEVE

It is most difficult for the parents of a child to comprehend the counterpoint between reality and their dreams, hopes, and aspirations for their child. There is a stark contrast between what they now envision for their son or daughter and what society has taught them to expect as the child's "normal" achievements. Dreams of college, business, or artistic success and, above all, spiritual and monetary success and financial independence vanish. In many instances, achievements by the retarded are not as much out of reach as they are diminished in varying degrees. In many cases, the capacity to benefit from education is still within the reach of the retarded. Employment is a goal that can be attained. Individual artistic or other abilities can be nurtured and achieved. Today, many of the retarded function independently in everyday life within our communities. These "normal" achievements are available to many of the retarded, provided training and education, coupled with family love and community understanding are forthcoming.

SOCIAL RESPONSIBILITY

For the retarded child, the same rule of society regarding success applies as it applies to all of us, that being, success is the fulfillment of potential. Diminished intellectual functioning may lessen the potential but it does not alter the possibility of fulfillment.

Our responsibility as a society is to create and maintain a social climate in which all people – no matter what their mental capacities – can achieve to the best of their abilities. This is every person's right, and it is the obligation of government and society to assure that all have the opportunity to succeed, including the mentally retarded.

This social goal is the law of the land embodied in the Constitution's very purpose to establish Justice, promote the General Welfare, and provide the blessings of Liberty to ourselves and our posterity.

That these rights were denied the mentally ill and the mentally retarded during our nation's two-hundred-year history makes fulfillment of Constitutional

3. New York State Mental Hygiene Law, Sec. 1. 05, sub. 18.

purposes even more important today in light of medical, scientific, and educational advances.

Shamefully, despite our advances, elements of the past are still with us. Today, in our mental hygiene programs, we may have established chemical asylums through the use of psychotropic drugs to control mental illness, but we have not cured it. Many of our schools or developmental centers for the retarded do not develop or school their residents. The "out-of-sight, out-of-mind" hysteria of yesterday still comes to the surface at too many zoning board hearings on community facilities for the mentally retarded or the mentally ill. Our modern medical bureaucracies still address mental illness and mental retardation programs within the same context, calling them "programs for the mentally disabled," yet treatment modes and requirements of the mentally retarded and mentally ill exhibit more differences than they do similarities.

GOVERNMENT'S GOALS

Today, parents of the mentally retarded are faced with the mixed metaphor of "mental disability" programs and state laws written largely to accommodate those suffering from mental illness.⁴ State bureaucracies are, in almost every instance, structured to deal with all the "mentally handicapped," but the record shows they have failed to achieve a reasonable degree of success with any one disability within this broad range.

Despite billions of dollars spent over the past ten years, and the enactment of new and far-reaching legislation designed to aid the mentally ill and mentally retarded, New York today faces challenges to the quality of care in both institutions and the community by the courts and the federal government.

There are a number of goals which, when achieved, would overcome past failures to aid the disabilities such as mental illness, mental retardation, alcoholism, and drug abuse.

First and foremost among these goals is the necessity to create a separate agency for the mentally retarded with authority over programs and budget to deal with their special requirements.

Second; there is the necessity to reconfirm the State's commitment to the best suited care for each affliction, whether that care is in the community, in a hospital, in a local school or developmental center, or in a vocational rehabilitation program.

Third; there is the necessity to guarantee that the most appropriate education is made available to each handicapped child without cost to the parent, just as we have provided free public education to every other child in our nation.

Fourth; there is the necessity to challenge the increasing tendency of the federal government to impose artificial square footage and staff ratios upon state and local programs in order to qualify for federal Medicare or Medicaid funds.

Finally, there is the necessity to inform the public fully regarding mental retardation and its implications so that the capacities and limitations of the mentally retarded may be thoroughly undersotted by the community.

4. Augustus M. Jacobs, "Legal Aspects," 1 *Mental Retardation* (1969).

These goals are an outgrowth of my thirty-three years as a parent of a retarded child, as a founder of a community program for the retarded, and as a State legislator for twenty years. Most of all, these goals arise out of failure of the nation's second most populous state to properly minister to the needs of either the mentally ill or the mentally retarded.

In this article, there will be a review of legislation and public policy in New York State dealing essentially with the mentally retarded, which is principally within the realm of my experience. My concern about the problems and hopes of the mentally ill is no less acute than my concern for the mentally retarded. Our problems are representative of problems in other states, although the scope and size of New York's program is the largest in the nation. To the extent that New York has progressed, it has done so carrying a burden of 60 institutions for the mentally ill and the retarded, and a state bureaucracy numbering more than 60,000. The 1976 Department of Mental Hygiene budget exceeds \$1 billion.⁵ To the extent that the State has failed to deliver services, in almost every instance mandated by the Legislature, that failure can be attributed to bureaucracy as well as institutional overhead.

PARENTAL RESPONSE

The community mental health movement evolved out of a broad citizen and professional concern for the mental health of the population during the 1950's. This was paralleled by a parent movement for development of programs geared for children in the community with mental retardation. This parent movement sought better conditions for the mentally retarded in the community and in the state schools. Both movements arrived at essentially the same conclusion for each group of clients, that being, the community offers the best hope for rehabilitation of the mentally ill and habilitation of the mentally retarded. These efforts were successful in promoting legislation and advancing the cause of the mentally retarded. Both movements were aided by three coinciding events: the use of tranquilizers to control acute and chronic mental illness; a realization that hospitals housing the mentally ill are in themselves a detriment to recovery and a contributing cause of patient deterioration; and the civil liberties movement which recognized and promoted the rights of mental patients.⁶ These events determined the course of legislation for the next decade.

BARRIERS TO CHANGE

One of the barriers to change has been the size of the bureaucracy. In 1955, the population of New York's mental hospitals reached 93,000 persons while the state schools for the mentally retarded only housed 21,000.⁷ By 1960 the population in the hospitals had dropped to 89,000 and by 1967 to 80,000.⁸

5. *New York State Executive Budget, 1976.*

6. Jim Klurfeld, "Who Is to Care for the Mentally Ill?" 2 Empire State Report 47 (March, 1976) [hereinafter cited as Klurfeld].

7. *New York State Executive Budget, 1955.*

8. *New York State Executive Budget, 1960.*

The population in the state schools rose to 28,000 in 1967. Ten years later, the inpatients at the state's psychiatric centers number 30,000. The institutionalized mental retardates had been reduced to under 20,000.⁹

By comparison, California, the nation's most populous state, had a hospital population of 40,000 patients in 1955. This was at the height of its institutional program. Today, California's hospital population numbers 5,000.¹⁰

New York's prognosis was and is most affected by the size of the problem and the nature of the bureaucracy that had been created to take care of it. The Department of Mental Hygiene is New York's largest agency in employment and, in fact, employs more people than do 37 state governments. The Department's budget of more than \$1 billion is larger than the total budgets of 16 states.¹¹ The Department is a bureaucracy deeply entrenched and politically potent, with centers widespread throughout the state.

Numbers do not speak to the quality of programs either in the institutions or in the community. After 1967, large scale "dumping" of patients from the psychiatric centers into the communities was largely responsible for the dramatic population drop in those years since 1955. However, this was without regard to adequate and proper programs for post-institutional care and supervision. The failures of this period were well documented by *The New York Times*, *The Albany Times-Union* and other journals throughout the state.

A "high-level member" of the Department of Mental Hygiene has said,

The theory of the Department then was to throw as many people into the communities as possible and that would force the local communities to provide the Facilities and services for those patients. The plan was a disaster. The communities did not respond. Instead of the hospital back wards, community back wards, called mental patient ghettos, were created in many communities.¹²

Public tolerance of all mental disabilities had been limited by the failure of the State of New York to release patients to the community with proper aftercare. The aftershock of the "deinstitutionalization" program for the mentally ill has adversely affected community-based programs for the mentally retarded. The stigma of mental illness immediately puts citizen reaction to all Department programs, particularly those relating to deinstitutionalization, on the defensive, and resistance is strong. Community hostels, half-way houses, sheltered workshops, and other local programs in and near residential zones all face this resistance. Unlike mental illness, which may be cured or stabilized, or may be simply a periodic malady, mental retardation is a lifelong condition that does respond to intensive education, training, and treatment which can allow the afflicted to reach a functioning level within society. The mentally ill as well as the mentally retarded have been cheated by the failure to obtain community acceptance.

The State's inability to follow up programs with sufficient funds and support services has inhibited and eroded whatever willingness the local govern-

9. *New York State Executive Budget, 1970.*

10. Klurfeld, *supra* note 6, at 49.

11. Susan Page, "3-Way Split of Department Draws Support," *Newsday*, February 7, 1977, p. 13.

12. Klurfeld, *supra* note 6, at 48.

ments might have had to contribute to community programs, whether for the mentally retarded or for the mentally ill. Even the Community Mental Health Services Act,¹³ enacted in 1954 to provide State funds to support community efforts at establishing alternatives to institutionalization, and the new Unified Services Law of 1973¹⁴ were big disappointments. By failing to apply the stimulus and incentive, as well as pressure on localities to develop such alternatives, the Department of Mental Hygiene did not fulfill its purpose. The burden on local taxpayers for social services, including Medicaid, and educational and other municipal services for the mentally retarded, has also been an inhibiting factor because of local government's share of the cost of these services to new residents in the community.

Further complicating New York's movement toward quality services, humane treatment, and effective programs for the mentally retarded has been an overcommitment to brick and mortar. In an effort to improve institutional conditions while at the same time reducing inpatient population, New York embarked, in the last decade, on a building program¹⁵ to replace outdated and outmoded psychiatric centers and developmental centers. As these new buildings come on line -- up to 10-12 years after conception -- the State finds that they are out of conformity with new federal guidelines for intermediate care facilities and, more importantly, out of step with the community care concept. This has left the state with under-utilized new centers, unable, in light of the current fiscal crisis, to staff them or to improve the older facilities still housing the mentally ill and the mentally retarded. This is attributable to the failure of the State's program of "deinstitutionalization."

LEGISLATIVE IMPROVEMENTS

Despite these formidable obstacles, we have made headway since the 1950's when the availability of quality services was negligible. Considering that it was not until 1962 when my bill¹⁶ was passed mandating that State institutions provide training and education and not merely custodial care and treatment, one can appreciate the many positive changes that have been made in a relatively brief span of time.

We have witnessed a major shift in philosophy, implemented in large measure by legislation, away from the massive institutional fortresses toward smaller community residences. We have worked to achieve a rather wide and, in many cases, comprehensive range of services for the mentally retarded and their families, including for the first time residents living in the community.

These advances extend to several areas:

- The delivery of services has been modified and directed into the community.
- Income benefits have been extended to the retarded to facilitate their independent living in the community.

13. New York State Mental Hygiene Law, Sec. 190, added by Laws of 1954, Chapter 10, Sec. 1.

14. New York State Mental Hygiene Law, Sec. 11.19, 11.21, 11.23.

15. 1968 N. Y. Laws, c. 359.

16. 1962 N. Y. Laws, c. 350.

- Alternative living styles for the retarded have been explored and often embraced.
- Significant preventive programs have been implemented.
- Attempts have been made to simplify program funding mechanisms.
- Consumer awareness has grown and support has built for the rights of the mentally retarded.
- A movement has developed to bring retarded individuals into the "mainstream" of "normal" living in our schools and communities.

Despite the many dedicated and well-meaning individuals within the Department of Mental Hygiene, the well-entrenched bureaucracy as a whole -- the largest and most costly in the country -- has been the source of many dismal failures in terms of providing care for the mentally retarded. Instead of dwelling on the errors and criticisms of the past, perhaps we should focus on the successful programs and policies that resulted from the inadequacies of Departmental actions.

Much of the force behind gains in the development of programs for the mentally retarded has been the growth of community movements. The New York State Association for Retarded Children (ARC), the first parents' organization of its kind in this State, was formed at a time when ". . . there wasn't a single clinic for the retarded in the United States, not a single sheltered workshop, not a single class (except in New York City) for trainable mentally retarded, not a single hostel or group home."¹⁷ The year was 1949. Out of the frustration of countless concerned parents and friends over the years has emerged a forceful network of 58 county chapters which serves 14,000 people a day in various programs, from recreation to vocational training to daily living skills. Its humble beginnings were, indeed, just that -- two parents who could find no school programs for their retarded children. Today, the voices have multiplied, and so has the availability of programs.

Legislation, both State and federal, has played a most important role in shaping the direction of care for the mentally retarded. Such early federal actions as the 1935 Crippled Children's Program,¹⁸ which provided for diagnostic and treatment services with funding shared by the State and federal governments, and the 1943 amendment to the Vocational Rehabilitation Act,¹⁹ which provided job counseling and placement, were the initial moves of consequence in the area of mental retardation legislation on the federal level. The latter act was significantly amended again in 1955²⁰ to reflect more aid channeled to voluntary agencies, universities, and the states for programs which would benefit the handicapped. Six years later, the President's Panel on Mental Retardation was established by President John F. Kennedy to focus on the needs of the retarded. These first efforts ushered in a period of broad federal participation in which aid to the mentally retarded was offered through various programs.

17. Task Force Report, *supra* note 1, at 3.

18. U. S. House of Representatives, Report No. 91-1277, at 4715 [hereinafter cited as House Report].

19. House Report, *supra* note 18, at 4716.

20. U.S. Department of Health, Education, and Welfare, *Summary of Selected Legislation Relating to the Handicapped, 1963-1967* (1968).

On the New York State level, the first major advances were made in the area of education and training with the establishment of classes for the mentally retarded. Although classes for the "educable" mentally retarded child -- one whose IQ is above 50 -- had been mandated in 1917, it was not until many years later that "experimental" classes were set up for the "trainable" child -- one whose IQ was below 50 -- in public schools. This marked the beginning of a flood of valuable legislation that was to follow in the years ahead in which provisions for school space, transportation, and State aid were achieved.²¹

Interestingly, the validity of the IQ-based definition for "trainable" mentally retarded persons had undergone some serious reevaluation in light of recent disclosures. Reports indicate that retesting of some "trainables," after they were exposed to a working and social environment, showed an increase in the IQ score. The Department of Mental Hygiene presently analyzes skills and other criteria in addition to IQ scores to determine placement in programs.

EDUCATION AND TRAINING

Modest legislative changes provided for schools to contract with other agencies for educational services when they themselves could not provide such services. The law providing that State institutions be used for training and education as well as for care and treatment represented a crucial shift in emphasis. This was an important acknowledgement that custodial care was no longer enough.

This notion was carried further in subsequent legislation, including a 1966 law²² which required the Department of Mental Hygiene to offer the same training and education in State schools for children aged 5-21 that they would be entitled to receive in the local school districts. The same provision was made applicable to state hospitals in 1968.²³

The renewed emphasis on education and training was further reflected in a series of laws²⁴ beginning in 1959 which required that transportation be provided for all mentally retarded children to public and private schools in the community.

From a financial point of view, several recent laws resulted in significant advancements in assuring that funds would be available to the handicapped for educational purposes. Enacted in 1966, Section 4407 of the Education Law²⁵ was set up to provide education funds of up to \$2500 for tuition only for a handicapped child who could not be served in public schools. This grant could be applied only to residential facilities.

A 1974 law,²⁶ positively affecting many mentally retarded children provided for double weighting for all handicapped children in the State aid formula for local schools. The formula change was a dramatic recognition of the greater cost to local school districts of education for the handicapped.

21. Task Force Report, *supra* note 1, at 2.

22. 1966 N. Y. Laws, c. 258.

23. 1968 N. Y. Laws, c. 869.

24. 1959 N. Y. Laws, c. 792; 1962 N. Y. Laws, c. 978; 1964 N. Y. Laws, c. 687.

25. 1966 N. Y. Laws, c. 842.

26. 1974 N. Y. Laws, c. 982.

One recently enacted law²⁷ may prove to be an effective way to channel funding to handicapped children who cannot be served by the public school system and heretofore had received only minimal aid to cover their higher expenses in obtaining private education. Since the State's education aid formula covered only those in public schools, many children could not benefit from that aid. The Legislature's intent was to eliminate the injustice by ending the need for parents to petition in Family Court for placement of their children in appropriate programs with State and local assistance. This bill further sets up an excess cost formula that assures a child's educational cost would be met.

SOCIAL SERVICES

Two noteworthy advancements in the area of social services deserve particular attention. 1966 stands out as the year when parental liability for mentally retarded adults was repealed.²⁸ Thereafter, retarded individuals with no personal assets and no capability of selfsupport qualified for public assistance in the form of Medicaid and subsistence payments under aid to the blind and disabled.

These actions were vitally important because of the hope they promised to the mentally retarded person who is not self-sufficient to avoid institutionalization. Further refinements have transferred these adults to a new federal program. Supplemental Security Income, and Medicare.

HOUSING

The area of housing became an important issue when gears were shifted to reflect a trend away from high institutional populations toward a community-based movement. Availability of housing in the community became a real concern when the deinstitutionalization trend began to take shape. Suitable accommodations had to be found in the community, but many obstacles stood in the way of providing community care for the mentally retarded.

Housing legislation that I sponsored, known as the Community Hostel Facilities Bill,²⁹ was enacted in 1967. This law provided for participation by the State in the acquisition or construction of community residential facilities for the mentally retarded. This State participation included one-third of the cost of construction or acquisition and one-half the cost of operations. Today, this hostel program, with 125 residences, is implemented through a direct rental agreement between the Department and voluntary provider groups.

A more recent development is a bill introduced in 1976³⁰ designed to remove zoning ordinance restrictions on certain homes for the mentally retarded. This was patterned after similar successful legislation enacted in California, Montana, and Minnesota.³¹ This legislation would exempt community hostels for the mentally retarded occupied by not more than 15 persons from local zoning re-

27. 1976 N. Y. Laws, c. 853.

28. New York State Social Services Law, Sec. 101.

29. 1967 N. Y. Laws, c. 576.

30. U. S. Senate, Intro. 8769 (1976).

31. Westchester County [N.Y.] Department of Planning, *Zoning for a New Kind of Family* (Occasional Paper No. 5, Fall, 1976).

strictions. There has been considerable community opposition to the community hostel program to the extent that many such hostels were compelled to locate in less than desirable locations.

PREVENTION AND DETECTION

Considerable advances have been made in the area of prevention and detection. As a result of my legislation enacted in 1964,³² an infant screening program was established in New York State to test all newborn children for phenylketonuria (PKU). PKU, when undetected and untreated, will result in mental retardation. This condition can be detected at birth by a simple blood test. An extension of this highly successful landmark program was instituted in 1974³³ to include testing for other diseases some of which can lead to mental retardation. The PKU law has served as a model in all other states and in many countries of the world.

Recent experiments have shown that hypothyroidism, another malady which can lead to mental retardation, can be detected from the same blood sample that is used in a PKU testing. Efforts are underway to have this added to the list of mandated tests.

A prenatal diagnostic test called amniocentesis, in which the mother's amniotic fluid surrounding the fetus is tested, is made to detect birth defects from examination of an unborn child's cells. Recent reports indicate the hope of *in utero* treatment of some maladies that are detected in this way. Thus, this technique could develop into a valuable preventive measure as well.

The Institute for Basic Research in Mental Retardation was created by legislative mandate in 1958³⁴ to undertake research in primary prevention, improved diagnosis, and other related issues.

Another development in prevention was the 1967 law³⁵ creating the New York State Birth Defects Institute. The Institute offers a diagnostic service for the detection of inherited diseases associated with severe mental retardation and other neurologic dysfunctions. This was further evidence of the State's commitment to the vitally important mission of preventive medicine.

FUNDING

An attempt was made in 1973 pursuant to the Unified Services Law to coordinate State and local services in the field of mental health into one system. Specifically, joint State and local planning, delivering and financing of all mental health, mental retardation and alcoholism services would be achieved. This coordinated planning would promote the development of a variety of services. This law was an attempt to provide a base of service to the mentally retarded, mentally ill, and alcoholic regardless of financing or jurisdiction, thus avoiding duplication and providing a shared overhead among the State, localities, and voluntary agencies.

32. 1964 N. Y. Laws, c. 785.

33. 1974 N. Y. Laws, c. 943.

34. 1958 N. Y. Laws, c. 912.

35. 1967 N. Y. Laws, c. 695.

Unfortunately, only five of the 62 counties in New York State have agreed to join the system.³⁶ There are a number of reasons for this, notably that long-term implications are difficult to evaluate and that such adoption of a county plan would represent a permanent commitment by the counties that they are reluctant to make. The varying modes of treatment for mental retardation and mental illness are also an inhibiting factor to the success of a unified services system. As a result of lagging interest by the counties, the Governor last year imposed an 18-month moratorium on new applications to enable the commissioner of Mental Hygiene to examine the entire system of service delivery.

One measure of the Department's neglect of mental retardation services is exhibited in the local assistance program where, of the \$107 million appropriated, \$21 million is allocated to mental retardation programs serving 20,000 mentally retarded in the community. Equally important, comparing local government support for mental health programs and mental retardation programs shows that more than 75 percent of local matching monies for community mental retardation programs are derived from voluntary organizations, not local tax levy funds. Mental health community programs, however, garner an overwhelming share of their local matching support from tax levy funds. This serves as further example of the mental hygiene establishment's continuing neglect of mental retardation programs.

Two laws enacted in 1974 deserve mention because of their proposed impact on the community movement. Chapters 620 and 621 of the laws of 1974 were designed to facilitate the deinstitutionalization of chronic patients of the Department of Mental Hygiene. Chapter 620 provided for an allocation of 100 percent of the net cost of Mental Hygiene services in the community. Chapter 621 provided for the funding for a period of five years of the costs of social services to an individual released into the community. A minimum of at least five years of residence in an institution was a requirement for this funding.

These laws, also covering the mentally ill, facilitated the transition of the mentally retarded individual to community life. Funds were made available under this legislation for the support of the individual while residing in the community. In addition, provision was made for their treatment, care, training, and education. Serious problems have emerged, however, and the State's "assurance" has been strongly criticized by consumer groups due to the State's method of calculating its commitment after voluntary agency funds have first been exhausted.

A distinction is created by Chapters 620 and 621 between institutional residents placed in the community and the mentally retarded who have always lived in the community. The latter group includes children of parents who had refused to institutionalize their children, and, at their own expense, supported them and attempted to train, develop, and provide support for them. While institutionalized residents now in the community receive full funding, community residents who are mentally retarded have few and inadequate programs available to them.

WILLOWBROOK CONSENT DECREE

The effectiveness of the parents of the mentally retarded in fighting for

36. *New York State Executive Budget, 1976* at 320.

adequate care for their children is apparent in light of important developments in recent years.

In 1972, the New York State Association for Retarded Children (ARC), together with parents and guardians of 18 residents of the Willowbrook Developmental Center, initiated an action in the U.S. District Court for the Eastern District of New York³⁷ to shut down the facility on the ground of inhumane conditions. The parents sought to transfer the mentally retarded residents to other more desirable facilities, including community residences and hostels.

The suit was successful, and an order of the court, known as the Willowbrook Consent Decree, was signed in 1975 by the Hon. Orrin Judd. The Willowbrook Consent Decree directed far-reaching improvements and changes. The Decree specified minimum educational services, developmental plans for all mentally retarded residents, and improved staff-patient ratios. Progressive deinstitutionalization was emphasized in the Decree by specific directive for a timetable.

Unfortunately, compliance with the Decree has been agonizingly slow, and non-compliance with some directives of the Decree was tantamount to contempt. A major breakthrough was made when the Court pinpointed specific improvements that had to be made. A deadline was set by the Court for their implementation. It is significant that the Court in its decision has dramatically acknowledged the need for vast improvements in the system.

ADVOCACY

In recent years, the Boards of Visitors of all state institutions have assumed greater responsibilities as advocates for the retarded. Under the provisions of Chapter 574 of the Laws of 1975, a minimum of three of the seven members on each board must be parents or relatives of patients. The remaining membership must be composed of persons having an active interest in or professional knowledge of mental illness and mental retardation. Under Chapters 338 and 340 of 1976, boards are required to make an unannounced visit every three months and are empowered to investigate cases of patient abuse or mistreatment. Certainly, the effectiveness of these changes has yet to be proven.

A law enacted in 1975³⁸ is significant in that it required that all local and unified services plans for mental health, mental retardation, and alcoholism be formulated and developed with the participation of consumers, consumer groups, voluntary agencies, and other providers of services.

The Mental Health Information Service (MHIS)³⁹ was created in 1964. Its direct and immediate goal was to advise patients of their civil rights. Throughout the succeeding years, its powers have been broadened substantially. In 1976, a law⁴⁰ was enacted requiring the MHIS to investigate cases of patient abuse and to institute legal action where necessary to safeguard patients' rights. Patient abuse is too prevalent a problem in too many of the institutions. Further, the

37. Index # 72civ356civ357.

38. 1975 N. Y. Laws, c. 516.

39. 1964 N. Y. Laws, c. 738.

40. 1976 N. Y. Laws, c. 334.

MHIS is empowered under the law to provide legal counsel for any patient who is not represented in such abuse cases.

OTHER NEW LAWS

Another "comprehensive package" of Mental Hygiene bills was enacted in 1976 seeking to improve and implement the State's program in the areas of our concern. The major provisions of these laws are as follows:

- A New York State Conference of Local Mental Health Directors was created to advise the Commissioner of Mental Hygiene; the Conference was empowered to review rules and regulations promulgated by the Commissioner and to make recommendations.⁴¹
- An individual written treatment plan was required for each patient or resident of an institution.⁴²
- A Program Development Grants Fund was established to give local government up to 80 percent of the "up-front" costs for developing community facilities and programs.⁴³
- A Council for Mental Hygiene Planning was created to develop a five-year Master Plan for the State.⁴⁴

IMPROVEMENTS NEEDED

Legislation such as this has been the result of a growing concern for improving services for the mentally retarded. However, there is still a long way to go to achieve a level of service which is adequate in many of the service areas, including education. Congressional findings outlined in the federal Education for All Handicapped Children Act of 1975 expressly set forth that "the special educational needs of [handicapped] children are not being fully met." The findings further stated that

all handicapped children [should] have available to them . . . a free appropriate public education which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected, to assist states and localities to provide for the education of all handicapped children and to assess and assure the effectiveness of efforts to educate handicapped children.⁴⁵

This statement focuses on the inadequacy of educational services for the mentally retarded, but its message could surely be applied to a multitude of services which are deficient.

41. 1976 N. Y. Laws, c. 331.
 42. 1976 N. Y. Laws, c. 332.
 43. 1976 N. Y. Laws, c. 333.
 44. 1976 N. Y. Laws, c. 441.
 45. Pub. L. No. 94-12, 94th Cong., S. 6.

DEPARTMENT BREAKUP

Indeed, many of the needs of the retarded continue to go unmet. One striking example of failure to meet the needs of the mentally retarded was the incumbent Governor's veto two years ago of my bill creating a separate Office of Mental Retardation which was overwhelmingly adopted in both houses of the Legislature. Since then, the Governor may have come to realize that the massive bureaucracy is unresponsive to his goals or the requirements of the Willowbrook Consent Decree. In his 1977 annual message to the Legislature, the Governor recommended a breakup of the huge agency into three separate offices. These three separate offices were designated as Mental Retardation-Developmental Disabilities, Mental Health, and Alcohol and Substance Abuse. (A separate autonomous office of drug abuse is presently within the Department of Mental Hygiene headed by an appointee of the Governor).

This action is in stark contrast to the Governor's May, 1975, veto memorandum of my separate office bill in which he said

The sponsors and supporters of these measures believe that by the creation of an office with a narrower mission than that of the Department of Mental Hygiene, services for the mentally retarded would be improved.

This concept, however, is not a sound one. Retardation is a symptom of many different underlying problems; a manifestation of medical, educational, physical, psychological and emotional problems. It requires a multi-disciplinary approach to educate and care for a mentally retarded person so that he can function to his fullest capacity, hopefully as a self-sufficient member of the community. It is imperative to bring all medical, educational and social disciplines to bear on the problems of each such individual. The arbitrary separation of mental retardation would merely frustrate a comprehensive treatment plan and fragment the delivery of service to the mentally retarded and developmentally disabled. . . .

It is estimated that the creation of the proposed office would cost the State \$4-\$7 million *with no increase in services* represented by this sum. This new structure also would undoubtedly divert attention and manpower into organizational and jurisdictional matters and away from the care, treatment and education of the retarded for some time to come. . . .

The bills before me today assume that the future operations of the Department of Mental Hygiene will not vary from the past. This is not, and will not be so. Such performance will not be tolerated.⁴⁶

In addition to being a marked change from the Governor's previous opposition to a separate office, drafts of his proposed legislation suggest that he is still adhering to the "mental disabilities" approach by keeping the three autonomous agencies he now proposes functioning under the title of Department of Mental Hygiene. The Department would be headed by a troika of three commissioners who would supervise central services to the institutions and the State's local assistance efforts under the Community Mental Health Program.

In both the Governor's message to the Legislature and his special health

46. Governor Hugh L. Carey, *Veto Memorandum #1* (May 6, 1975).

message, he paraphrases what parents of the mentally retarded have been observing for years and what the Legislature told him two years ago by passage of my separate office bill. The Governor said in his State of the State Message

The proposed reorganization will result in each agency being accountable for services to its clients. It will assure common standards, procedures and requirements for all child-caring facilities and end the contradictions and confusion which hinder efficient program operations and sound decision-making.⁴⁷

He further explained in his special health message

A separate office for the developmentally disabled will enhance our abilities to fully implement the Willowbrook Consent Decree and the State's five-year plan for compliance with Federal standards governing care in developmental centers, both of which are nationally recognized as models for improving care for the mentally retarded. A separate office will reinforce existing trends toward the establishment of services to the developmentally disabled which are distinct from the psychiatric model of care and treatment and more carefully tailored to the needs of the office's clients.⁴⁸

While the Governor's long-awaited recognition of the need for a Department of Mental Hygiene breakup is welcomed, as an advocate for true separation of Mental Retardation programs from the Department of Mental Hygiene, I find in the Governor's draft legislation a number of serious pitfalls which may be resolved during the current legislative session. Observers have noted that his reorganization proposal coincided with a recent action instituted by parents involved in the Willowbrook suit. to cite the State's leadership for contempt for failure to implement the Willowbrook Decree. Whatever the motivation, separation of mental retardation programs from the massive Department of Mental Hygiene is the means to begin to achieve a functioning system of mental retardation services in New York State.

OVERVIEW

In any exercise of this nature, there are, hopefully, benefits to the reader. In this case, the author also benefited. My review of legislation brought into stark focus what I had always suspected but had never outlined: much of the mental hygiene legislation enacted in the past 15 years in New York State required the Department of Mental Hygiene to do something it had the power to do but had failed to accomplish. Most recent examples of this phenomenon include legislatively mandated individual treatment plans for Department clients, a clinical records system to report treatment to patients and parents, a five-year plan, and a greater contribution by local mental health directors in the Depart-

47. Governor Hugh L. Carey, *State of New York Message to the Legislature* (January 5, 1977).

48. Governor Hugh L. Carey, *State of the Health Message* (Special Message to the Legislature, February 17, 1977).

ment's decision-making. These and other administrative changes were requirements that any medical or developmental facility might have been expected to have accomplished but which the New York State Department of Mental Hygiene had failed to achieve.

Often, this piecemeal approach to solving governmental problems, particularly in the mental hygiene program, has served to distract the Legislature from its proper institutional function to take action on policy, program and structure. Further, the finger-in-the-dike approach of passing laws mandating administrative functions breaks down and blurs the lines of responsibility within the administration of the Department itself. In short, some legislative actions may have led to as many internal administrative problems as they solved.

Certainly, the separation of mental retardation services from the Department of Mental Hygiene is a crucial matter which deserves legislative attention. There are others as well. Hopefully, the parents of the retarded child mentioned in the beginning of this article will find refuge after this session of the Legislature in a separate autonomous office for mental retardation. Only then will programs be directed specifically toward their child's unique needs. After all, that is what we have been working to achieve all these years.