

Certain Real Problems in the Development of Community Programs for the Medical Care, Education, and Training of the Mentally Retarded

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Solutions for five difficult administrative problems offered here stem from a broad field experience in this troubled area of new but wide public health interest.

✻ Several years ago in Massachusetts, as in other parts of the country, new legislation was enacted as a result of the urging of the Association for Retarded Children and other interested groups. These laws provide for adequate community programs for the special education and training of retarded children.

The new legislation sets up state subsidized special-class programs for the educable retarded and trainable retarded children in every community and makes it mandatory that each school system provide special classes whenever there are five or more such children in a given community. In June, 1956, there were 131 communities conducting special classes, with 520 educable and 81 trainable classes. There were 7,282 children enrolled in educable classes, 756 in trainable classes. In all, there were 574 teachers of special classes in the state.

The Massachusetts Departments of Education, Mental Health, and Public Health met for 18 months during 1954 and 1955 in an interdepartmental committee to develop regulations for screening, study, and placement of children in special education. Heretofore, the screening and study of children for placement in special educational facili-

ties were carried out under regulations developed in 1919, when the Binet intelligence test was first introduced into Massachusetts on a large scale. The 1919 system provided for a group of so-called traveling school clinics comprised of psychiatrist, psychologist, and social worker who visited, on request, each year various school systems to examine within the school itself children referred to it by the school superintendent. Reports and recommendations were prepared and returned to the superintendent.

The Department of Mental Health had practically abandoned its traveling school clinic program during World War II because of the shortage of personnel and had, since 1947, been planning with many groups for a revision of the screening program. A system of mental health centers was introduced in Massachusetts in 1952, with mental health consultation services available to school systems and diagnostic services available to children and parents in the community.¹ By 1956 there were 16 such mental health centers established in the state, with several more planned for the coming years.

Since 1919 two developments in schools had occurred which made it particularly unrealistic to continue the traveling school clinic pattern; first, the development of school health programs with school physician services, periodic physical examinations, school nursing with its close contact with parents and

family physicians, and second, the development of school psychology with testing and guidance programs available within school systems themselves. Most schools handled their special class placements by themselves. Furthermore, studies carried out in the late forties in the largest traveling school clinic showed that 85 per cent of the children referred for questions of special class placement were not "retarded" according to the medical concept of retardation, but had behavior disorders, learning disabilities, psychoneuroses, personality disorders—problems for a child guidance clinic or mental health center.

The traveling school clinics were serving more as administrative and technical aids to the school administrator, rather than as medical services to the child and its parents, and were impeding the development of school psychology in Massachusetts. The clinics performed three basic operations—the physical examination of the child, the psychometric examination of the child, a sociopsychiatric study of the child and the family. The Department of Mental Health recommended to the interdepartmental committee that these three functions be divided: (1) physical examination to be performed, on referral, by the family physician or by special clinic facilities, such as pediatric or neurologic clinics, or, in lieu of these, by the school physician; (2) that the basic psychometric screening examination be administered in the school system itself by a qualified school psychologist, approved for administering such examinations by the Department of Mental Health; and (3) that the sociopsychiatric evaluation of the child be made by the mental health center or by other psychiatric services as desired by the parent, with the mental health consultant from the mental health center available to the school administration to review and evaluate findings of the school concerning each child. The

responsibility for declaring the child educably or trainably retarded—in other words, for placing the child in school—should be entirely the superintendent's.

This new system went into effect in 1955, along with the mandatory provisions of the new law that school systems should determine how many children there were in need of special education or training and should provide classes for them.² This new plan had many advantages over the old system. First, the medical relationships with the child and parents were removed from the school administration setting, so that the parents might have a private medical relationship within which to examine the problem, air and work through the many difficult feelings and attitudes which accompanied their problem, and to plan realistically for the future of their child. Second, the basic screening instrument, the intelligence test, is in the hands of educators, who use it widely to determine the most appropriate curriculum and teaching approach for all school children. Test findings in the school setting can be correlated with findings of clinical studies and their implications for the educational and other needs of the child discussed and reviewed with the school by the mental health consultant. The new plan brings together many people who are concerned from various points of view with the particular child—the school teacher, school nurse, school psychologist, school administrator, family physician, mental health center, various community agencies, and the parents.

During the two years of experience

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with this new plan many serious problems have come to light which impede development. Some of these have recently been described in a report of the spring (1956) meeting of the Northeast States Government Conference on Mental Health.³ There are five problems which seem most in need of study and solution.

The first problem is that there is a general confusion concerning the conditions that are embraced by the term "mental retardation." The recent study by Gruenberg, et al., in Syracuse highlights the confusion, indicating to us that different groups of professional people from education and health are indeed counting different types of disorders, labeling them all "mental retardation."⁴

The intelligence quotient, derived from whatever source, can serve only as one factor in the differential diagnosis, study, and planning for a particular child. The early notion that intelligence quotients are distributed on a normal distribution curve through the population results in tremendous confusion, such as publication of statements that 3 per cent of the population is "mentally retarded."⁵ In Massachusetts this results in statements that there are approximately 60,000 mentally retarded in the state. These figures are of little practical use to the administrator and are indeed misleading to the public, which assumes there is a distinct medical entity known as "mental retardation." Actually, the National Association for Mental Retardation in its literature states that there are at least 70 distinct medical disease entities which may have as one of their accompanying factors a condition of "mental retardation."⁵

The problem of definition becomes particularly important when we consider the large group of so-called educably retarded children, children who score I.Q.'s in the borderline range. Many

of these children are recognized by the trained child psychiatrist or pediatrician to have clearly defined diseases and deficits on an organic or emotional basis or both. Others, however, are showing learning disabilities and deficits in functioning on intelligence testing which, however, does not represent their true intellectual potential. This is well recognized in child guidance clinics where the clinical psychologist frequently reports that the child is functioning below his true capacity.

Changes in intelligence test scores are commonplace in child guidance clinics, as emotional factors and others, including hearing and seeing deficits, are corrected. Nevertheless, those who administer programs of special education for retarded children cling to the test score as their justification for decisions concerning the school placement of the child. In the average special class program, the casual observer will see more striking differences between the trainable and educable groups than between the educable group and a class of "normal" children of the same age. We are not so concerned with the problem of definition in the trainable area, where we are dealing with children who have extremely severe physical, mental, and emotional handicaps.

We have tried to tackle this problem administratively in Massachusetts by defining community programing as not for "retarded children," but for children "in need of special education." A superintendent has to declare whether first, a child is in need of special education and, second, whether the special education is of the educable or trainable variety. This is without reference to intelligence quotient, per se; nevertheless, intelligence quotients still remain the main determinants of these decisions. The following case illustrates how this problem of definition of mental retardation affects the individual child.

This example doubtless can be multiplied many times in Massachusetts as it can be elsewhere.

A physician referred a 14-year-old boy to the Mental Health Center in June as a last resort. The youngster had been progressively unable to learn in school, had been the previous year placed in a special class program following testing in the school which revealed an I.Q. below 80, which the school administrator was using as a definite indicator of "mental retardation" and need for special education. During the year the child was very unhappy, feeling discriminated against, the butt of ridicule in the neighborhood.

The parents were extremely anxious, overprotective, convinced that the experience in the special class, where, as the boy stated, he was with children that were "different," was, in fact, impeding his progress. Conference with the school administration in June, when the boy was reassigned to the special class for another year, resulted in a tremendous emotional upset on the part of the boy and the parents. At that point, they consulted their family physician who referred them to the Mental Health Center.

At the Mental Health Center the youngster was seen to be an anxious, inhibited child who was unable to tell his story either in the presence of his mother or alone. He did state that he knew he was not like those other children in the class, said that he had not learned anything during the year, and spoke of his embarrassment. He drew pictures for the doctor. The pictures were not those of a mentally retarded child, but those of a neurotic child with anxiety and inhibition. Psychologic tests, conducted in a nonthreatening atmosphere after a friendly relationship had been established, revealed an average intelligence in a youngster with an overwhelming anxiety reaction and a learning disability.

The functioning of the youngster in the test situation previously given in the school is understood only in relationship to his emotional difficulties. The child is obviously in need of special education, but is not "mentally retarded." Certainly he is retarded in his functioning in school situations which other children are able to handle successfully. We cannot criticize the school, for in fact, from their point of view, the child is "retarded," based on the school's standards and expectations, and the test performance in the school situation.

This leads us to a second overwhelming problem in this field; namely, there is little or no attempt to apply sound knowledge of emotional and cultural factors in the growth and development of children to the field of the mentally retarded. This may seem like a sweeping statement, but nevertheless it can be documented in Massachusetts. There is as yet little application of modern child psychiatry to this field. We are beginning, as exemplified in the previous example, to bring in modern child psychiatry and psychiatric casework, making these available to school people, parents, children, and others concerned with this problem.

There is a striking absence of modern social casework in this field. We are dealing, obviously, with chronic disease and should have centers for chronic care of these children, focusing on the role of the parents in child management, realizing that growth and development of these children take place in slower, altered fashions. There is a crying need for good, solid, family casework programs. If we studied our populations in state schools in the higher I.Q. ranges, we would find these children are in state schools more because of family disorganization and disintegration than because of the particular intelligence test score which the children exhibit. Of course, the state schools began originally

as an effort to provide special education and training technics for children in need of them and who are able to profit from them. The state school populations are changing now, becoming filled more with severely damaged children in the extremely low I.Q. ranges.

A further example of how this lack of appreciation of emotional factors may influence the whole approach to special education is presented in the following case: A shy, anxious little girl who scored an I.Q. of 74 had failed to learn during the previous school year. On consultation with the Mental Health Center, it was decided that this girl could profit from special education. It was fully recognized that the child's emotional difficulties were hampering her performance. It was felt that the special attention that she would receive in the small class would be of help to her. The child began special class, the mother reporting that the child was coming home from school for the first time in her life happy and really looking forward to the next day. The child's self-confidence began to develop and her performance improved.

In the middle of the year, the school psychologist retested the child, found the child performing at an I.Q. level of 88. From the Mental Health Center's point of view this demonstrated that the special education the child was receiving was indeed beneficial to her. However, the school administrator became extremely concerned that a mistake had been made in placing the child in the special class in the first place inasmuch as she was scoring in the high 80's. Second, he was concerned whether the child should at this point be transferred to her regular class inasmuch as she was not "mentally retarded." The mental health consultant focused on the needs of the child the fact that the special class program was obviously beneficial to the child and treated the issue of "mental retardation" as an issue quite irrelevant

to the child and only of concern obviously to the administrator.

The anxiety of the school administrator and resultant tendency to rigidify the special education program results stem in part from a lack of knowledge of the importance of emotional and cultural factors as they affect the performance of the child. The mental health consultant serves an important educational function in his work with the school system as he helps them plan for the individual child.

With "special education" a function of the public schools and medical care a function of health agencies and physicians, we are faced with the third problem in community programing. It is unclear who is responsible for the professional care of the retarded child. This seems to result from the fact that we have not decided whether we are dealing primarily with a medical problem or an educational problem.

To whom can the parents turn when concerned with the growth and development and the performance of their child? Ordinarily the parents will turn to their family physician. He is busy and obviously proper attention to these problems takes a lot of professional time, not only in study of the child but most important, in orientation, education, and casework with the family. Who is going to take the responsibility for the long-range supervision of the growth and development?

We do not have any special agency set up in Massachusetts today for this purpose. The state schools might develop outpatient clinic facilities, providing medical supervision much as has been developed successfully in the care of chronic illnesses, such as rheumatic fever, orthopedic diseases or cerebral palsy. There is tremendous resistance to developing such services inasmuch as the state schools are overwhelmed with problems of internal organization, staff deficiencies, etc. There is, as mentioned

above, a serious lack of social workers trained in modern casework who are interested in this field.

The best illustration of the seriousness of this problem in Massachusetts comes from the direct experiences of the parent groups themselves and the Associations for Retarded Children. These are developing rapidly; in certain communities some are functioning as Parent-Teacher Associations to special education programs, while others are concerned with the development of diagnostic centers, preschool nursery schools for retarded children, day care, summer camps, and sheltered workshops for older retarded children. The parents' group is gradually developing an intense feeling of frustration because as they move from group to group, from the educators to the physicians, to public agencies and private agencies, trying to get programing started, they get "the run-a-round." It seems to us that the reason for this is that there is a lack of clarification as to which agency is responsible for over-all programing.

Responsibility is defined by institutional functions. The superintendent of each state school is responsible for the children in his charge, the patients—and we use the word "patient" here not feeling sure that all children in state schools are commonly referred to as "patients." Public school superintendents are responsible for the students in special education programs. They wonder if it is correct that they should be responsible for the trainable group of children who are so damaged and so many of whom will eventually be institutionalized. "Is this a proper function of a public school system?", ask many superintendents with some justification, based on experience with groups of these extremely damaged children.

Another reason for the lack of programing and the frustration of the parents' group is the fourth problem we face; lack of trained personnel—pro-

fessional people to do the job in the community and a lack of a body of sound knowledge and established practices which can be shared by professionals from the various disciplines and which can serve as guides for further research. Obviously, the field of mental retardation is a special field, but at the same time it demands the cooperative work of people from many more generalized fields, such as child psychiatry, pediatrics, education, occupational therapy, psychiatric social work, research physiology, and biochemistry. Obviously, the lack of trained professionals may be part of the general lack of trained professionals in the health and education fields. This is a serious problem and demands development of recruitment and training programs throughout the states.

Development of such programs for the field of mental retardation is currently tremendously hampered and will undoubtedly continue to be so by the fifth and, in some ways, the most serious problem in this field—the firmly entrenched attitudes and assumptions concerning mental retardation, in both the public and professional communities, which slow the development of adequate programs and impede treatment and research. Retardation is closely linked to failure and attitudes of repression and avoidance are commonplace when it comes to failure. There are, as well, fears of being influenced in a demonologic fashion by exposure and contact with retarded children.

The field has a very low status ascribed to it by the community and by professionals. People in the field are thought often to be inferior themselves, both within the education and medical professions. The concept of mental retardation is intimately related to expectations of the community within which the child is functioning.

All our attempts to develop epidemiologic studies of mental retardation point

to this fact, as published prevalence rates of mental retardation are highest in the school-age child, the problem for all practical purposes disappearing when the child is outside of the educational system. Mental retardation is less a medical entity than it is a sociocultural designation. In this sense it poses for the mental health people a problem somewhat similar to that of the designation, "juvenile delinquency," which is not a medical designation but a legal designation.

Not until we are able to redefine the problem using modern concepts of growth and development, both physical and emotional, combining knowledge of pediatrics, neurology, the learning process and psychopathology, can we remove this problem of low status ascribed to the field and enable professional workers to approach the problem

of mental deficiency with firm and forward-looking programs of community education, care and treatment of retarded children, and research programs which will point the way to the ultimate control of the problem through increased knowledge and preventive measures.

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Sanitary Engineer Certification Deadline Extended

The deadline for submitting applications for certification by the American Sanitary Engineering Intersociety Board under the "grandfather" clause has been extended from July 1 to October 1, 1957. Until that date, applicants who meet the basic requirements of graduation from an acceptable college of engineering, registration as a professional engineer, 15 years of acceptable sanitary engineering experience and who have attained recognized prominence in the field, may be certified without examination at the discretion of the Board. After that time applicants must take a written and oral examination. Application forms and further information from the Secretary, ASEIB, Room 1601, 33 West 39th Street, New York 18.