THE COMMISSION FOR HANDICAPPED CHILDREN

REPORTS TO

THE PEOPLE OF ILLINOIS

STATE OF ILLINOIS

AUG. 26TH 1818

DWIGHT H. GREEN, GOVERNOR

THE COMMISSION FOR HANDICAPPED CHILDREN

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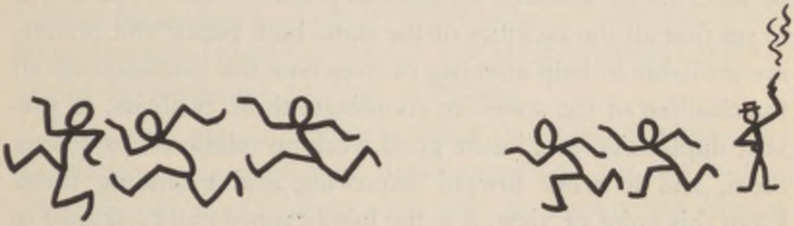
The Illinois Commission for Handicapped Children has thirteen members, including, *ex officio,* the Director of Public Welfare, the Superintendent of Public Instruction, the Director of Public Health, and the Director of Labor; and nine prominent citizens actively interested in the problems of handicapped children, who are appointed by the Governor for three-year terms. The present members of the Commission are:

MRS. HARRY M. MULBERRY, *Chairman,* Chicago
IRVING F. PEARSON, *Vice-chairman,* Springfield
BERT I. BEVERLY, M. D., Oak Park
ROBERT BELL BROWNE, PH. D., Urbana
ROLAND R. CROSS, M. D., Springfield
MRS. MARGARET POPE HOVEY, Chicago
ROBERT L. GORDON, Urbana
VERNON L. NICKELL, Springfield
FRANK A. NORRIS, M. D., Jacksonville
CASSIUS POUST, Springfield
EDWARD H. STULLKEN, Chicago
GERARD M. UNGARO, Winnetka
HENRY C. WARNER, Dixon

HOWARD E. M. MILLER, *Executive Director*

The Commission for Handicapped Children Reports

One of the fundamental ideas of democracy is that every child is to be provided an opportunity equal to that of his fellows. The broad objective of the Illinois Commission for Handicapped Children is to make this idea apply to a group of children who might otherwise be left behind at the start. This group, the particular concern of the Commission, is made up of children who are handicapped because of a physical or mental deviation.



A handicap may be defined as any disadvantage that renders achievement, or especially success in competition, more difficult. The implications of the definition, in terms of the exceptional child, are far-reaching. Any child is not only a child, but a future adult, who should be able to take his place ultimately in the adult world. And that world is one in which his achievement and his ability to compete with his fellows will measure not only his own personal happiness, but his usefulness to society and his contribution to the common good. A child who is born with a handicap, or who acquires one, represents more than a personal tragedy. He represents a potential encumbrance to society, should he be unable to make his contribution to the community. He represents a financial burden on the community, if he becomes dependent. He represents loss of labor and loss of potential creative skill. He represents a possible social problem, should the frustration of his handicap make him delinquent.

The efforts of a society in counteracting as far as possible the disadvantages of handicapping conditions to individuals are services to the community as a whole, not just to the specific individual served. Few members of a democracy would be unwilling to offer such services from purely altruistic motives. But an effective program is best accomplished on the basis of a thorough examination of its reasons for being, and awareness of all its possible ends.

The Illinois Commission for Handicapped Children has therefore two essential purposes—related and intertwined, to be sure, but nevertheless separate in point of view. The first is to see that all the facilities of the state, both public and private, are available to help alleviate or overcome the handicaps of all the children of the state—to coordinate those facilities, to prevent duplication and insure good working relationships among them, and to work toward improving and extending them. From this point of view, it is the handicapped child's chance to live a good life with which the Commission is concerned. Its efforts are bent toward enabling him to share with personal satisfaction in the life of the community and toward helping him prepare himself for and secure suitable work, so that he will be spared the humiliating necessity of being dependent upon others for his daily needs.

The second purpose of the Commission, which is really the first approached from another angle, is to salvage for the community the potential contributions of its handicapped children, relieving it, so far as possible, from the burden of the economic and social dependency of this group of future adults.

For the sake of clarity in discussing the work of the Commission, the better approach seems to be from the point of view of the individual child; but it is important to keep in mind the fact that as the child's interests are served, so the interests of the community are served.

A child's needs cannot be divided into mutually exclusive departments. His well-being depends upon so many factors, and those factors are so closely associated and have so great an effect upon one another, that no factor alone can be said to conrol his wholesome adjustment to life. A crippling orthopedic condition is more than a mechanical handicap to a child. In preventing his engaging in normal physical activity, it is a physical handicap. If it excludes him from participation in group activities, it is a social handicap. If it interferes with his education, it is a mental handicap. If it keeps him from preparing for future gainful occupation, it is an economic handicap. And if he is set aside from his fellows because of it, made an object of pity or derision, it may be an emotional handicap as well. The same statements apply to any of the handicaps, physical or mental.

Naturally, the large units by which our modern complicated society is governed must be departmentalized for the sake of efficiency. It would be impracticable in a state like Illinois, which has nearly two and a half million children, for all of the services which the State provides for their education and welfare to be carried on by one agency. The intention of the legislature in setting up the Illinois Commission for Handicapped Children was to provide a single agency which would be concerned with the total welfare of exceptional children, who require more specialized assistance than do normal children; an agency which, through consultation and advice, could coordinate the services of the various State departments concerned with their care and could help those departments to improve their services to this special group.

The group of children who are the concern of the Commission is large and varied in its membership. No two children have identical problems. No child could be said to be typical. But what happens to one handicapped child may serve to show to some extent the kind of questions that may come up in caring for any of them.

A hypothetical case might be that of a fourteen-year-old boy—we will call him Joe—who lived with his widowed mother in a town of about 10,000. One day Joe's mother noticed that he was limping, and when she asked him why, he told her his leg hurt. The pain didn't go away, and after a few days, Joe's mother took him to the doctor. After giving the boy a thorough examination, the doctor diagnosed his condition as possible tuberculosis of the bone of his leg and recommended specialized care. Since there was no orthopedic specialist in the community, he advised Joe's mother to keep him in bed for a couple of weeks until the next clinic would be held in the town by the Division of Services for Crippled Children of the University of Illinois. At the clinic, Joe was examined by a pediatrician and an orthopedist, who confirmed the family physician's diagnosis. The Division recommended that Joe be taken to another town to a private hospital which had an excellent orthopedic service. Because Joe's mother was unable to pay for his expensive treatment, the Division arranged for it—placing him in the hospital and paying all of the expenses incidental to his illness. During the six months when Joe was hospitalized, he continued the high school work he had just begun before he became ill. His study was supervised by a teacher assigned to the hospital by the public schools, under a special education program which is supported, in part, by the State. The social service department of the hospital kept in touch with his mother, letting her know how he was progressing, and arranging for her periodic visits.

When the orthopedist who was Joe's physician decided he no longer needed hospital care, the problem of his convalescence came up. Joe was in a body cast, and his mother was not strong enough to lift him. Since it seemed advisable, furthermore, for him to be near the hospital during his convalescence, so that he could receive continued follow-up supervision in the outpatient department, the hospital social worker arranged for him to stay in a private convalescent home. The Division of Services for Crippled Children continued to pay his expenses.

After another six months or so, Joe was out of his cast and could walk on crutches with the support of a brace, which had been provided for him by the Division. His mother could give him the care he needed then, and so Joe went home. A nurse from the Division called on Joe's mother, to give her advice about looking after him. Carrying out the recommendations of the orthopedic specialist, the nurse arranged for Joe to go to the Division clinic periodically, as long as it was necessary.

At the beginning of the next school year, Joe was ready to go back to high school, but he could not negotiate the stairs to get around to classes. The Division nurse consulted the local superintendent of schools and found that, although the school district in that town had no special arrangements for the education of crippled children, it was their custom to send them to the crippled children's class in an adjoining district, where special facilities were available. Joe was duly entered in the special class, his local district paying the adjoining one for the normal costs of his education, and the extra costs, including his transportation to and from the school, being paid out of State funds after approval by a supervisor from the State Superintendent's office.

By the time Joe finishes high school, he will probably be able to walk without crutches and without his brace, although he will still be handicapped by a very pronounced limp, since one leg will be shorter than the other. The Division of Services for Crippled Children will notify the Division of Rehabilitation (a program financed jointly by State and Federal funds) when Joe is ready for vocational training, giving them a record of their knowledge of Joe and the extent of the crippling effect of his handicap. Upon Joe's application to the Division of Rehabilitation, he will be given aptitude tests to determine what special skills he has that will help him to make a living, and counsel in his choice of an occupation. When Joe, under the guidance of the vocational counselor, has decided upon his career, the Division of Rehabilitation will provide whatever training he needs for it. They will pay his tuition to go on to school, and, if he must go away from home for his training, his maintenance while he is away. When he has finished his vocational or professional education, Joe will be assisted in finding a job by the Division of Rehabilitation.

Although this story of Joe indicates ways in which the various departments of the State government, and private agencies, come to the assistance of a handicapped youngster, minimize for him and his family the burden of his handicap, and help him to become an able and self-sufficient citizen, it does not show on the surface the work of the Commission for Handicapped Children. The Commission has been at work for Joe and others like him, nevertheless. The Division of Services for Crippled Children, through which Joe received constant care during his illness, is supported in part by an appropriation made by the General Assembly on the recommendation of the Commission after long research and consultation with experts in the field. His schooling, made possible under the legal provision for State aid to local communities for additional costs of educating handicapped children, was carried on through a program of special education which the Commission has done much to improve and develop. The staff of the Commission works constantly with the State departments and private agencies which concern themselves with cases like Joe's, helping them to coordinate and improve and expand their programs. It carries on research and stimulates public interest in the existing facilities and the unmet needs of all handicapped children.

The act of the 62nd General Assembly in 1941, which established the Commission for Handicapped Children, defined for the Commission seven duties. In a report of this length, it would not be feasible to attempt an enumeration of all the activities which have been entered upon under each provision of the law. Much of the Commission's work, furthermore, is of such a nature that it could equally well be placed in any of several of the seven categories. For the sake of illustration, however, various projects will be described on the following pages, classified by the sections of the law under which they seem most appropriately to fall.

A. To coordinate the administrative responsibility and the services of the four State departments and officers represented in its membership insofar as they relate to the well-being of handicapped children as defined in this Act and to compose any differences that may arise between such departments and offices.

An illustration of the way in which the Commission carries out this first duty specified by the law is the improvements made in recent years in the administration of the program of State assistance for special education. In 1941, when the Commission was beginning its work, the State law provided for reimbursement of local school districts for excess costs of educating crippled children, up to a maximum of $300 per child. Funds for such reimbursement were administered by the Department of Public Welfare, which of course had no facilities for determining the quality of any educational program. The education of handicapped children, while it presents certain problems outside the usual concern of the public schools, is in the last analysis an educational problem, and cannot properly be administered by any department occupied primarily in other fields. At the instigation of the Commission, an interdepartmental committee was set up, so that the Department of Public Welfare could obtain the approval of the Office of the Superintendent of Public Instruction on local plans for special education before reimbursement was made. Arrangements were also made whereby the Division of Services for Crippled Children determined whether children for whom requests were made were sufficiently handicapped to require special education.

In 1943, the Commission sponsored legislation which made similar procedure a part of the legal requirements. Under this Act, reimbursement to a local district for special education could not be made until a plan for such special education had been submitted to the Director of Public Welfare, who was required to obtain the approval of the Superintendent of Public Instruction on the educational aspects of the plan and of the Division of Services for Crippled Children on the medical eligibility of the children to be educated. This law also made it the duty of the Superintendent of Public Instruction to supervise all classes and schools established for special education, to prescribe standards and approve such classes and schools, and to determine, before reimbursement could be made by the Department of Public Welfare, whether the child for whom the claim was made was handicapped and in need of and receiving special education.

To improve the program still further, the Commission sponsored legislation which was enacted by the Assembly in 1945, relieving the Department of Public Welfare of the duty of fiscal administration of the program. This most recent Act provides that the State Superintendent of Public Instruction will administer all aspects of the State's part in special education in local school districts, and instructs him to call upon other agencies and departments of the State government for appropriate cooperation.[1] The law now in force, therefore,

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[1] It should be noted that the various Acts discussed here contained provisions for improvement of special education offered to children in Illinois, other than those mentioned above. For the sake of illustrating the present point, only the pertinent provisions have been discussed.

places the supervision of education of handicapped children under the same jurisdiction as that of other children, where it logically belongs.

B. To stimulate all private and public efforts throughout the State in the care, treatment, education and social service of handicapped children and to coordinate such efforts with those of the State departments and offices into a unified and comprehensive program.

The Commission's most notable project in carrying out this charge of the law has been the Governor's Conference on Exceptional Children. It was with the hope of furthering public understanding of the problems of these children, of the resources and facilities available to meet those problems, and of the needs of such children which remain unmet, that the first Governor's Conference was called in June, 1942. The several hundred persons who attended the Conference included a large proportion of professional workers in the fields of health, welfare, employment, and education particularly concerned with exceptional children, as well as a number of interested laymen. The success of the Conference—its undoubted value in stimulating and coordinating public interest in the field—led to planning it as an annual event. The second Conference, held in December, 1943, was as signal a success as the first. During 1944 and 1945, it was impossible to hold the Conferences because of wartime regulations on meetings. The third one, however, is to be held on June 14, 1946. Its theme will be "The Community's Opportunity."

At the first Governor's Conference in 1942, a part of the afternoon session was devoted to discussion of legislative proposals relating to handicapped children. At that time, it was suggested that a committee should be formed of representatives of private agencies in the state which deal with handicapped children or children generally. This committee was planned as an advisory body to the Commission which would offer an opportunity for all interested groups and individuals to discuss the legislative needs of exceptional children and enlist the support of other organizations in their proposals. During the following summer the group was organized by the Commission as the Citizens' Committee on Legislation for Exceptional Children. Three meetings were held that year to discuss legislative measures for presentation to the General Assembly of 1943. The Committee was called together again in the summer of 1944, prior to the General Assembly of 1945, and will be called again in the summer of 1946. It serves as an effective clearinghouse for ideas and information about the problems of handicapped children, and stimulates agencies and individuals to work together toward the improvement of existing conditions.

C. To promote special classes and competent individual instruction for all types of handicapped children in all parts of the State and to arrange for the special training of teachers for such classes.

The Commission for Handicapped Children has been instrumental in bringing before the legislature certain bills enacted by the 63rd and 64th General Assemblies (1943 and 1945) which have greatly improved the educational opportunities for handicapped children in Illinois. In 1943, the Crippled Children's Act was amended so that it applied not only to orthopedically crippled children, but to *all* physically handicapped children, epileptic, speech defective, tuberculous, cardiac, and so forth, except the blind and visually defective and the deaf and hard of hearing, who had long been provided for under another law. State aid to the extent of $300 per year per child was made available to local school districts to cover excess costs of the education of all children so physically handicapped that they cannot profit by the normal school program. The law also provided for the improved supervision and administration discussed above under Section A.

A second Act of the Assembly in 1943 was the one providing for State assistance to local districts for special educational facilities for the mentally handicapped. This law specifies that local districts which set up plans for classes for mentally retarded children which meet with the approval of the Superintendent of Public Instruction may be reimbursed for the excess costs up to $100 per year per child.

Improvement of administration of the State assistance provisions for educating handicapped children was accomplished through action by the 64th General Assembly in 1945. Some of the new provisions are discussed above under Section A. In addition, measures were enacted to place the education of all types of physically handicapped children under one provision, and a specific addition to the budget of the Superintendent of Public Instruction was made so that qualified specialists in education of exceptional children could be added to his staff to assist local school administrators. The School Code was amended to allow local districts to offer special education to all types of physically handicapped children from the age of three years and to be reimbursed by the State for approved programs for preschool handicapped children.

The new hospital school for severely physically handicapped but mentally educable children, which is now beginning operation, will be discussed later in the report, but it should be noted here that it also is an example of improved educational provisions for handicapped children which the Commission has sponsored.

In the course of the past few years, the Commission has done a considerable amount of advisory work with the various state teacher-training institutions in regard to special training for teachers planning to work with handicapped children.

D. To promote adequate provisions for medical diagnosis and the treatment of handicapped children in all parts of the State; provided, that the diagnosis and supervision of educable mentally handicapped children shall be performed by physicians qualified by training and experience in the study of psychiatry.

Citing examples of the Commission's work in promoting adequate provisions for medical diagnosis and treatment of handicapped children is somewhat more difficult than illustrating other phases of the Commission's program where more concrete instances made the point clearer. The Commission's policy in this field has been to encourage the expansion of the work of existing agencies to include larger numbers of cases and to make better service available. Since this effort is carried on largely through conferences of staff members with other interested persons, it would be not only difficult but unfair to claim the improvements in medical service in the planning of which the staff has participated, as accomplishments of the Commission. The following projects, however, exemplify this phase of the Commission's activities.

Prior to 1943, the Division of Services for Crippled Children was supported entirely by Federal funds available under the provisions of the Social Security Act. In 1943, partly through the efforts of the Commission for Handicapped Children, the

General Assembly made an appropriation of $225,000 of State funds to make possible an extension of the services of the Division in providing medical diagnosis and treatment for crippled children on a state-wide basis. Another larger appropriation was made by the State in 1945, for further extension of the Division's program.

The Commission's function as a clearinghouse for efforts in behalf of handicapped children served in the establishment of a cerebral palsy diagnostic center at the Illinois Surgical Institute. At the suggestion of the Commission, the Crippled Children's Committee of the Rotary Club of Chicago, which had expressed an interest in making some contribution to the welfare of cerebral palsied children, provided the funds for the training of an experienced worker with crippled children in the special problems of children suffering from this handicap. When her training was completed, the Rotary Club arranged to pay the salary of the worker at the Illinois Surgical Institute so that children with cerebral palsy can receive full benefit of the diagnostic services of the hospital in one coordinated department.

A continuing concern of the Commission has been the group of children who are acoustically handicapped and who, in order to benefit from an education and to adjust socially and vocationally, need specialized medical and related services early in life. It was at the instigation of the Commission that the Division of Services for Crippled Children added a program of medical diagnosis for these children to its regular clinical services.

Such publications of the Commission as *Children with Cerebral Palsy, The Epileptic Child in Illinois,* and *Blind and Partially Seeing Children in Illinois,* while they do not go into great detail on medical diagnosis and treatment, do point out the unmet needs. It is hoped that through their wide distribution they will stimulate efforts to improve existing conditions.

E. To promote vocational guidance, training, placement and social adjustment on an individual case work basis for all such handicapped children in need of such services and to promote facilities in boarding homes for the care of children maladjusted to their home surroundings.

Because of this specific charge of the law, and because vocational training is one of the important phases of any child's development, handicapped children as well as others, the Commission has had a continuing concern over the inadequacy of the present facilities in this field for handicapped children in Illinois. While the Division of Rehabilitation of the Board of Vocational Education provides for vocational guidance, training, and placement for handicapped children, its service is not available to them until they have reached the age of 16 and have left school. The early vocational guidance and training which is especially important for handicapped children is not feasible except as a local community service. Since it is recognized that the need of an adequate program of vocational guidance for exceptional children is a part of the total need for vocational services for all children, the Commission has recently enlisted the efforts of the Bureau of Educational Research at the University of Illinois in making a survey to determine the adequacy of the existing vocational services, particularly with regard to handicapped children, and the extent to which the guidance program at the local school level might be made more effective. The survey is now under way.

It is hoped that a result of this study will be the arousing of local interest in the subject—an awareness of the problems involved—which may stimulate communities to initiate programs of vocational service to children, or improve those which already exist.

F. To promote the establishment of a vocational school of the colony or village type for the temporary training of educable mentally handicapped children maladjusted to their home, boarding home or school surroundings who evidence or display symptoms of dependency or delinquency with the view of returning them to their homes, and from moneys appropriated for such purpose, to construct a building, or purchase or lease an existing building, or any suitable portion thereof, for such vocational school.

The validity of this undertaking as part of an ideal long-range program for educable mentally handicapped children has been questioned by most persons concerned with the problem. The special education law makes it possible for the public schools to set up programs for the training of such children, and related welfare, recreation, and guidance services should be developed in local communities. It is patently more advantageous for children to be trained in the community in which they live than for them to leave home to attend a state school, so that they have to make an adjustment to a new situation, and a second adjustment when they ultimately return to their homes. It appears that a new state institution for this purpose, in addition to being a highly expensive undertaking, would at best be but a stop-gap until such time as local services are available. At worst, it might deter the development of such services, which are rightly the responsibility of the local community. The Commission feels, therefore, that it is carrying out the spirit of the law by encouraging local provisions for the vocational training of the educable mentally handicapped child.

G. To study conditions relating to such physically or mentally handicapped children in Illinois and in other states continuously with a view toward improving the facilities and services available to such children in Illinois through recommended administrative and legislative action.

The new Illinois Children's Hospital School for severely physically handicapped children (mentioned above under Section C) is a concrete example of the operation of the Commission under Section G of the law. From the time that the Commission was created, it was aware of the special problem of children so severely handicapped physically as to be unable to be included in any school program, however efficient, set up at the local level. Children with normal mental capacity may suffer from conditions which medical care cannot help, such as muscular dystrophy, progressive muscular atrophy, cerebral palsy, spina bifida, or residual paralysis from poliomyelitis, so that they require constant custodial care. Since the only state institutions which provide such care have been those designed to provide for children who are mentally deficient, mentally normal children with such severe physical handicaps have had to be cared for at home. This is not only a disadvantage to the child, who is denied the opportunity to be educated in accordance with his abilities, but it frequently places an intolerable burden upon his family, and, when the family is broken up by death, illness, or separation, leaves the child without a home.

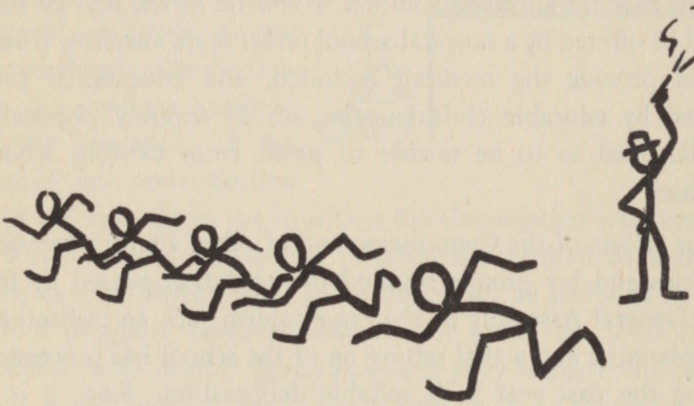
Awareness of the needs of such children, and of the lack in the state of facilities to meet those needs, led the Commission to enter upon a widespread study of the situation. Although there is no exact way of counting the number of such cases which exist, the careful estimates that were made indicated that it was appreciable. Methods of dealing with the problem in other states were studied, as well as the methods of private institutions which accept such cases when families are in a position to assume the great financial burden of private care. After long consultation with many workers in the various professions concerned with the problem, the Commission concluded that the ultimate solution would lie in the service that could be offered by a hospital-school under State auspices, which would provide the medical, custodial, and educational care needed by educable children who are so severely physically handicapped as to be unable to profit from existing school facilities.

The efforts of the Commission and of other vitally interested agencies and lay groups resulted in legislation passed by the 64th General Assembly in 1945 to establish such an institution. The planning and actual setting up of the school has proceeded during the past year with suitable deliberation. Since it is a pioneering effort, the first institution of its kind, careful consideration of every step in its organization is of utmost importance.

The hospital-school presents an excellent illustration of the function of such an agency as the Commission for Handicapped Children. The need having been demonstrated and the hospital-school having been brought into existence through the efforts of an agency concerned with fact-finding and stimulation, the hospital-school will render direct service under an administrative agency (the Department of Public Welfare). The Commission's responsibility from now on will be that of advice and consultation.

As every improvement in the condition of handicapped children is effected, the function of this Commission is altered—

perhaps broadened, perhaps narrowed. The millenium toward which it works is the time when no child in the state, whatever his handicap, is denied any opportunity which a democratic society can give him. We in Illinois are not yet near enough to the millenium to relax our efforts to reach it, but we are on the way. The interest and cooperative endeavor of a whole state are needed to smooth the road.



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