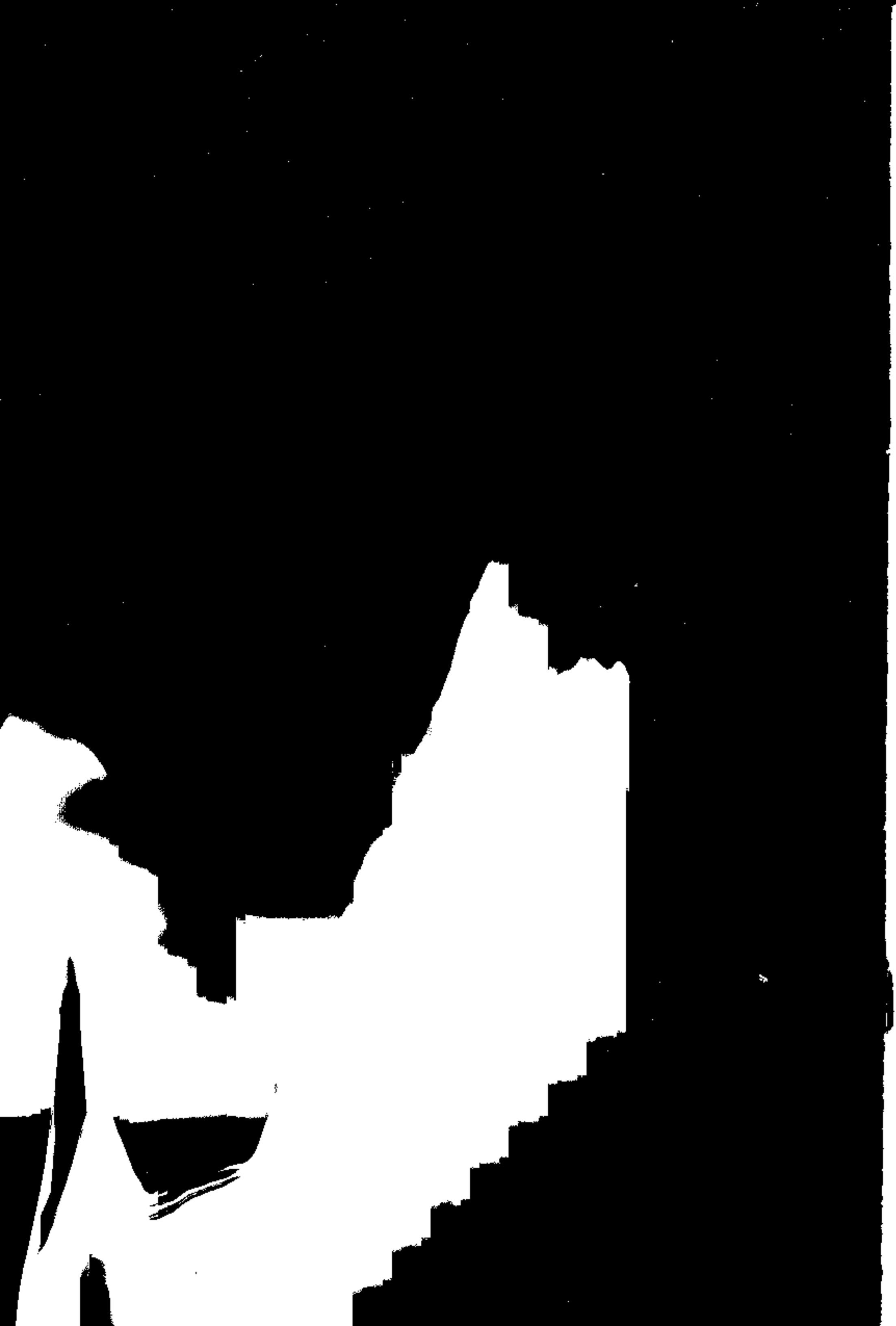

Federal Legislation

affecting the mentally retarded

1955-1967

An Historical Overview

by

Elizabeth M. Boggs, Ph.D.

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Federal Legislation

By ELIZABETH M. BOGGS, Ph.D.

The Kennedy years had a unique and powerful impact on public interest, professional opportunity, and official action in relation to mental retardation. Their very splendor has, however, somewhat obscured those events of the preceding decade that maximized the influence of President Kennedy's personal interest in the problems of the mentally retarded. When responding to the charge that President Kennedy gave to his Panel on Mental Retardation at their first meeting in October 1961, it chairman, Leonard Mayo said: "Mr. President, 'There is a tide in the affairs of men, Which taken at the flood, leads on to fortune.' This is such a time in the affairs of the mentally retarded." The "flood"to which Mayo referred was one that had been building since the mid-1950s; the triumphs of 1963 would not have been possible without the less publicized efforts prior to 1960.

To understand the 1960s it is important to understand something of earlier years. This is particularly so as we turn the corner to the 1970s whose events are so rapidly obliterating the memories of Camelot.

For purposes of brief review, pre-1945 may be called the *professional years,* 1945 to 1955, the *parents' years,* and the important interval from 1955 to 1960, the *congressional years.* In each of these periods new cohorts joined the growing armies of the concerned. As each period added new impetus to the crescendo of effort, parents, professionals, congressmen, and members of the administration were buoyed by the growing support of an increasingly informed and concerned public.

The federal program, as is proper in a democracy, has been one result of a combination of many forces interacting over many years, some steady, some transient, some central, some incidental. The total impact of these forces on the fortunes of the retarded cannot be delineated here. Nevertheless, it is important to note that federal directions identifiable as specific to the field of mental retardation are strongly influenced by two main ongoing phenomena: (1) the continuing and accelerating evolution of public investment, and particularly federal investment, in delivering health, education, and welfare services to an ever-widening general constituency; (2) the evolution of professional and informed lay opinion, based on experience with the mentally retarded in the classrooms and the institutions and later in the workshops, clinics, and other community service systems.

THE PROFESSIONAL YEARS

During the period prior to 1930 psychologists and educators in public and residential schools were in the ascendant in work for the retarded; they began to assume leadership comparable to that which had earlier been exercised primarily by medical superintendents. It was between 1909 and 1929 that Wallin, Doll, and, yes, Goddard preached the gospel of special education, which gave rise to pioneering public school legislation in New Jersey, Massachusetts, and a number of Midwestern states.

Thus, the 1930 White House Conference on Children and Youth represented the culmination of a quarter century of great professional productivity and enthusiasm in the field of mental retardation. Unfortunately, the significant recommendations built into the conference fabric by its subcommittee on mental deficiency were quenched by the overriding concerns of the economic depression of the 1930s, followed by those of World War II, with the result that people who have come more lately into the field are often unfamiliar with pre-Depression activities.

The years of the Great Depression were lean ones indeed for the major public programs—state residential care and public school special classes for the retarded. New construction came to a standstill just at the time the children born during the post-World War I baby boom came of school age. Under the pressure of rising regular enrollments the "luxury" of classes limited to 15 pupils yielded, and a new definition of "educability" began to be applied to the retarded. Under it, in some states classes previously established for "imbeciles" were discontinued on the grounds of their pupils' lack of progress in academic subjects.* Moreover, as mildly retarded youths and their families became the victims of rising unemployment, admissions from this group to residential institutions began to increase.

The austerities of World War II continued the prohibition on major construction and converted staff shortages based on lack of funds into staff shortages based on lack of available manpower. The demand for workers at all levels of skill was to have one positive consequence for the retarded, however. The professional workers trained in the 1920s who had kept their faith in the potential of the mildly retarded to make an economic contribution were rewarded, as young adults began moving successfully from special classes and institutions into the factories and armed forces. This phenomenon was to have important consequences for the state-federal program of vocational rehabilitation.

These fiscal crises of depression and war, accentuated by the lack of any significant federal cushioning, brought about a 15-year hiatus in the development of public programs for the mentally retarded along with a major gap in the continuous pattern of professional recruitment, especially in education, though the situation varied from state to state in accordance with the level each had achieved prior to 1930. The differences between states had yet to experience the smoothing effect of federal intervention in welfare, health, and later education.

Though massive federal funding activity in the various areas of health, education, and welfare was yet to come, and all federal activity in the functions constitutionally reserved to the states was more circumscribed than at present, we can nevertheless identify professionally initiated federal interest in mental retardation as long as a half century ago. Very early in its history, for example, the Children's Bureau initiated studies on the problems of the mentally retarded in the District of Columbia and in Delaware.[2] There are recurring evidences of the Children's Bureau's interest in the mentally retarded in the decades that follow, though it was not until the passage of the Social Security Act in 1935, with its provision for federal grants-in-aid to states for maternal and child health and welfare and services to crippled children, that the Children's Bureau had substantial funds with which to assist the states to respond to its stimulus.[24]

Similarly, the U.S. Office of Education, almost from its earliest years, had begun to document what states and local school districts were doing to educate handicapped children, including the retarded. Between 1920 and 1965, the results of no less than eight detailed surveys were published.[15] These figures, indeed, help us to document the regression brought about by World War II. In addition to monitoring the activities of state and local school authorities through such surveys, the Section on Exceptional Children and Youth, under the widely respected leadership of Elise Martens, began producing useful publications during the early 1930s. Indeed, one of these, *A Guide to Curriculum Adjustment for Mentally Retarded Children,* first issued in 1936, remained, even at the time of its reissue in revised form in 1950, a major resource for teachers.

The Bureau of the Census has collected some sort of data on persons with mental deficiency since 1840, and still includes special reports on institutionalized mentally handicapped in the publications resulting from its decennial activity. Annual enumerations of patients in state institutions for the mentally retarded began in 1926. With the establishment of the National Institute of Mental Health immediately after World War II, this function was assumed by its Biometrics Branch, to which we owe the fact that residential care is the most accurately documented of all services, public or private, in which the mentally retarded are enrolled.

The National Mental Health Act of 1946 also resulted in some support for projects affecting the mentally retarded. This act established the National Institute of Mental Health (NIMH) within the National Institutes of Health. NIMH was unique among the institutes (and so continued until its separation in 1968) in having and exercising authority to support services and training for services as well as research. The Mental Health Act was followed in 1950 by legislation authorizing the establishment of the National Institute of Neurological Diseases and Blindness (NINDB) to which was assigned, inter alia, responsibility for supporting research in epilepsy and cerebral palsy. Though mental retardation was not mentioned in either charge, both institutes were supporting some relevant activities during the early 1950s.

One of the most significant of NIMH's grants in the mid-1950s went to George Peabody College for Teachers, in Nashville, Tennessee, for a doctoral curriculum in psychology with emphasis on mental retardation. Many of the leaders in state and university programs for the retarded today are graduates of this unique program, which, in modified form, is continuing under funding from the new National Institute of Child Health and Human Development (NICHD).

The year 1970 was celebrated as "Rehabilitation's Golden Jubilee" in honor of the Industrial Rehabilitation Act of 1920, a direct precursor of today's Vocational Rehabilitation Act.[28] Federal aid for programs of vocational rehabilitation for the handicapped grew out of post-World War I efforts to extend to civilians the methods found to be successful in rehabilitating disabled veterans. Thus, the initial focus was on physical handicaps. During World War II, however, partly for the reasons outlined earlier, the Vocational Rehabilitation Act was amended to include the mentally handicapped as candidates for rehabilitation services.[1,21] The significant and influential federal publication, *Vocational Rehabilitation of the*

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*By 1950 only a handful of local public day school classes specifically for the "trainable" had survived. Notable were the Alta Vista School (later named for Louise Lombard) in San Francisco, the Beta School in St. Paul, and two classes in Jersey City.

Mentally Retarded, by Salvatore G. DiMichael,[8] which appeared in 1950, documented the first successful demonstration efforts and pointed the way to the expansion and improvement of methods of training, counseling, and selective placement of the retarded. Dr. DiMichael left the federal vocational rehabilitation program to become the first executive director of the National Association for Retarded Children (NARC) on January 1, 1954.

THE PARENTS' YEARS

As the postwar years brought increased numbers of handicapped children onto the scene, their parents soon discovered the quantitative and qualitative inadequacy of facilities and services that had been allowed to retrogress during the stresses of depression and war. First individually, and then collectively, especially after 1950, when the NARC was formally organized, their voices were increasingly heard. The impact was felt first at the state level, where new or revised mandates were enacted to ensure the retarded their rights to free public education. The overcrowding and the burgeoning waiting lists at residential institutions were no longer borne in silence by the families of the affected.

Federal programs were not the first target, yet those that monitored or interacted with state agencies could scarcely shut their ears. It was not long before the professional staff members of the relevant federal agencies began to respond in accordance with the measure of responsibility or authority generally vested in each.

For the Office of Education, for example, direct financial aid was not authorized, but its chiefs, Arthur Hill and Romaine Mackie, wrote and spoke to their colleagues, encouraging them to respond in a professionally creative manner to the new situations and to utilize the resource represented by organized parental support of public school special education programs.[1'] The office's extensive and ambitious study of the preparation of teachers of handicapped children, made possible by the support of the Association for the Aid of Crippled Children (AACC), a private foundation, got underway in 1953 and put the office in the position to be the first proponent of specific substantive legislation on behalf of the retarded, in response to the congressional interest manifested during the latter half of the decade.

The Children's Bureau, after ascertaining what little the states were at that point doing for the mentally retarded with Children's Bureau grant money, used its existing grant authority to promote specialized diagnostic clinics for the mentally retarded.

The number of mentally retarded rehabilitants under the state-federal rehabilitation program began its initially slow rise during 1946. The future would depend largely on the image of the mentally retarded person as a responsive candidate for rehabilitation, as seen by the professional rehabilitation Worker. It was significant, therefore, that, during 1953, the director of the federal Office of Vocational Rehabilitation, Miss Mary Switzer, issued an unmistakable clarion call to her colleagues at the first general session of the annual conference of the National Rehabilitation Association. It is no coincidence that during this same year a number of the local units of the NARC started sheltered workshops as training facilities for the rehabilitation of the mentally retarded. The 1954 amendments to the Vocational Rehabilitation Act gave Miss Switzer and her colleagues additional and more appropriate resources with which to

stimulate their state counterparts toward more vigorous action on behalf of the retarded.

President Eisenhower considered rehabilitation of the handicapped a sound investment, and this program grew and flourished during his administration. During 1954 the President also endorsed the first observance of National Retarded Children's Week, since then observed annually at Thanksgiving time by NARC. During 1958 he appointed the president of NARC to the President's National Committee for the 1960 White House Conference on Children and Youth.

At its formation in 1950 the NARC had given research for prevention and amelioration of mental retardation a prominent place among its constitutional purposes and had proceeded soon thereafter to organize a scientific research advisory board, under the chairmanship of Dr. Grover F. Powers, professor emeritus of pediatrics at Yale. This body, after reviewing the paucity of apparent interest in retardation as a subject for investigation, proposed in 1954 that a survey be conducted of the status of research in this field.

Dr. Richard L. Masland, a young neurologist on the faculty of the Bowman-Gray School of Medicine, who was later to become the director of NINDB, initiated the survey in 1955, under NARC auspices with foundation and, later, NIH support. He himself concentrated on the biomedical aspects. Not content with reviewing the literature, Dr. Masland visited a number of university research centers for the purposes of identifying relevant research which might not be so viewed by the investigators.

Concurrently, NARC was focusing the attention of Congressman Fogarty on mental retardation. Mr. Fogarty's interest in NIH had already been aroused, and he easily saw his way clear to earmarking some funds for mental retardation research in the NIH appropriation for fiscal 1956. Specifically, he earmarked $500,000 to NINDB and $250,000 to NIMH. A member of the National Advisory Mental Health Council of that period recalls some consternation in that body at the prospect, because NIMH staff members privately doubted whether as much as $250,000 could be well spent on a subject as unglamorous as mental retardation. Dr. Leonard Duhl, however, saw the opportunity to redress a needed balance in NARC's survey by offering to fund a behavioral component. Thus a second project, conjoint with the Masland undertaking and under Masland's general direction, was mounted by Seymour Sarason and Thomas Gladwin on the behavioral and psychosocial factors in mental retardation. The reports appeared in several journals and were eventually published in book form.[17]

Dr. Powers, on behalf of NARC, also lent support and encouragement to Dr. Glidden Brooks, who was representing another group of parents—those who had formed the United Cerebral Palsy Associations—in promoting a novel project, the first massive longitudinal study of perinatal development ever attempted in America. Inaugurated in 1959 under the direction of NINDB (now NINDS), the so-called collaborative perinatal research project involves some 14 collaborating medical centers in various parts of the country who jointly enrolled 58,000 pregnant women for observation of the pre- and postnatal conditions and circumstances affecting them and their children from early pregnancy until the child reaches 7. In addition to special ancillary research projects, each center carried on observations according to a common protocol. By 1970 millions of observations made on these mothers and their children were available to be analyzed by modern data processing and searched for correlations that may provide some clues to causes. The program also illustrates the tremendous range of investigations that have relevance to the cause, prevention, and treatment of mental retardation.

In the meantime, following the Masland-Gladwin-Sarason missionary work, which pointed up the challenges, NIMH began receiving and funding an increasing number of research grant applications related to mental retardation. During fiscal 1960, for example, it supported 49 projects in basic and applied research primarily or secondarily related to mental retardation for a total of more than $1.1 million.[20] This represented a substantial increase compared to the 7 projects totaling $121,064 cited by NIMH Director Robert Felix in 1955.[30a] The total NIMH extramural research budget for the year 1960 exceeded $23 million. The stimulus for this growth came also directly from Congress. During the 1950s parents and interested professionals banded together in every part of the country and were joined by public-spirited citizens less personally affected; it was inevitable that they should bring their cause to the attention of their elected representatives and find among them a few who saw the need for action. One such was Congressman John E. Fogarty of Rhode Island, who, in December 1954, was invited to speak at a meeting of Rhode Island parents, one of whose leaders, Arthur Trudeau, was an old school friend. Fogarty, a humanitarian confronted with the peculiarly difficult problem that mental retardation presents to the afflicted and their families and appalled at its apparent social neglect, knew that he must act responsibly. A month or so later his sense of the problem, and of the role he might play in contributing something to its solution, were accentuated by an article appearing in *Columbia*, the house organ of the Knights of Columbus.[5] The article, written by the father of a retarded child, featured activities on behalf of the mentally retarded by a number of prominent Catholics. Among them were the then Archbishop Cushing, counsellor to the Kennedy family, and Dr. Salvatore DiMichael, executive director of the NARC. In Dr. DiMichael, Fogarty found a person able and eager to give him the nationwide perspective on the problem which he sought.

THE CONGRESSIONAL YEARS

Fogarty's first task was twofold: to determine what in fact was being done within and by federal agencies and to stimulate those having implicit responsibilities to pursue and discharge them more explicitly. For this mission he was strategically situated as the chairman of the Subcommittee on Appropriations for the Departments of Labor and Health, Education, and Welfare. The latter was a new department, which had been created by Act of Congress, less than two years before.

During the hearings on Tuesday, February 8, 1955, Mr. Fogarty caught Secretary Oveta Culp Hobby off guard when he asked, "What are we doing on behalf of these millions of (mentally retarded) children in this country? This is the first year I have asked this question, so it is a little something new, I know." In reponse to Mrs. Hobby's somewhat evasive answer, he went on:

> "I think it will take a combination of two fields of research and study; one education, and one, a health program of some kind.
>
> So I am going to ask not only you, but the Surgeon General and the Commissioner of Education, and anybody I can think of that might know something about this problem, about what we are doing and what we can do. I hope we can do something and I hope that the Committee will set aside a sum of money this year to start a program for these mentally retarded children.[30a]

True to his words, Fogarty quizzed the agency heads as they came up in turn to justify their respective portions of the HEW budget. Of them all, that veteran champion of children, Dr. Martha Eliot, chief of the Children's Bureau, came off the best, not so much for what had been done but for seeing where more could be done.

The March 1955 issue of *Children Limited*, the NARC newspaper, announced under a Washington dateline of March 18 that "History was made for retarded children on a national scale today when the House Appropriations Committee urged an all out attack on the 'great and growing problem.' " In addition to earmarking $750,000* to launch new research in mental retardation, the committee also made clear that it expected the Office of Education to present a "real program" when it came before the committee in 1956. The corresponding Senate committee, headed by Lister Hill of Alabama, a well-known friend of medical research, sustained the proposed appropriations for mental retardation, as did the respective houses of Congress.

Within the year the Office of Education came forward with several proposals—Fogarty's committee was able to respond immediately to one of them by funding the previously passed but as yet unimplemented Cooperative Research in Education Act with a fiscal 1957 appropriation; the major portion ($675,000) was earmarked for research in the problems of educating the mentally retarded. The Office of Education also proposed new substantive legislation to authorize the commissioner to make grants to universities or state departments of education to pay fellowship stipends to students preparing to be teachers of the retarded or leaders in educational activities on their behalf.[16]

At that time precedent had been set for federal aid to students in shortage professions in health, but applying federal aid to the field of educational manpower could have constituted a "first." Because enactment of the legislation proposed was delayed it remained for the 1958 National Defense Education Act to break this barrier.[16]

The bill for training in education of the mentally retarded, first introduced by Fogarty and Hill in 1956 and reintroduced the following year in the 85th Congress, was backed by the administration of President Eisenhower. It passed readily in the Senate with Hill as advocate, but encountered stiff opposition from Representative Graham Barden of North Carolina. At that time, Barden who chaired the House Committee on Education and Labor, made it clear that his dissatisfaction with the Supreme Court's school desegregation decision would be reflected in opposition to almost any new education legislation. Only late in 1958, during the last days of the 85th Congress, did the valiant efforts of Representative Carl Elliott of Alabama, supported by NARC, secure the passage of a somewhat modified version of the bill, sponsored by Congressman George McGovern of South Dakota. This legislation formed the foundation of Title III of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963-(Public Law 88-164).

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*Part of these funds was used to support the nationwide survey of research sponsored by the NARC, described earlier; part was used to start the technical projects of the American Association on Mental Deficiency, an interdisciplinary professional organization founded in 1876. These projects were continued under the direction of Dr. Herschel Nisonger, in Columbus, Ohio, until his death in 1969.

At that time it was broadened to cover all major categories of handicaps. It was later incorporated into Title VI of the Elementary and Secondary Education Act. During fiscal 1970 more than $30 million was distributed for the training of personnel in special education of the handicapped (of all types), as compared to the modest million with which the program was inaugurated in fiscal 1960. Many of today's programs are possible however because key college and state and local administrative positions are held by a new generation of men and women who received their full-time graduate training under the original 1958 law—Public Law 85-926.

The new resources for training were indeed urgently needed; the postwar resurgence in special education programs in the public schools and other settings brought with it an unprecedented demand for new professional manpower. By the time Public Law 85-926 was passed, the enrollment in special programs for the retarded had increased by 150% over the preceding decade. The overall 10-year increase in pupils served by special education generally was 132%, more than three times the rate at which the total public school enrollment was increasing as a natural reflection of population growth. These increases continued into the 1960s. Retarded children accounted for about half the total special class enrollments.[15]

A corollary to this expansion was the increase in membership and effectiveness of the Council for Exceptional Children (CEC), the major professional association in the special education field. As it moved, during the 1960s, to strengthen its headquarters staff in Washington, to develop the basis for bipartisan support in the Congress, and to provide an acceptable focal point for the coordination of input from the various "categorical" voluntary organizations interested in education of the retarded, deaf, blind, emotionally disturbed, physically handicapped, and "children with learning disabilities," CEC became the central force in securing a series of spectacular advances in federal support of education of handicapped children, including the mentally retarded. A resume of these advances through 1967 has been prepared by one of the key actors in the drama, Dr. Edwin W. Martin, Jr.[16]

The Comprehensive Approach

Though Mr. Fogarty's first moves in 1955 focused on education and health research, his line of questioning at that time indicated his recognition that mental retardation is a problem whose various facets must be tackled from the vantage points of different agencies. This view was vigorously advocated by NARC and endorsed by the Department of Health, Education, and Welfare, which in 1955 established an internal committee on mental retardation "with the view to providing additional national focus, expansion, and improvement of the services, programs and activities of its operating agencies in this field." Meanwhile NARC formalized its views on the need for a comprehensive program in a detailed statement forwarded to Mr. Fogarty in January 1956.[6] It called for intensified action not only in the Office of Education and NIH but also in the Children's Bureau, Office of Vocational Rehabilitation, and the Bureau of Public Assistance. NARC's suggestion that an additional million of Children's Bureau funds be made available for special projects to extend diagnostic and counseling services for young mentally retarded children and their families was incorporated in the HEW budget for fiscal 1957, thus launching a program that, during 1970, partially supported 150 clinical programs in all parts of the country.[24]

NARC's 1956 proposals also touched on some substantive matters not directly tied to appropriations. One of these had to do with the interpretation of the Hill-Burton Act of 1946 as amended by the 1954 Hospital Survey and Construction Act. The original act excluded from federal assistance in construction "any hospital furnishing primarily domiciliary care." By regulation of the Public Health Service, all institutions for the mentally retarded were excluded categorically on the assumption that all were primarily "domiciliary" in nature. Despite Hill's clear statement in a letter to NARC in 1954 that he, as co-sponsor of the acts, had no intention of making such an exclusion of treatment facilities for any group, it was not until 1959—1960 that a reasonable revision in interpretation was finally achieved.

In 1956, NARC also backed the proposed change in the Social Security Act which authorized what is now known as the Adult Disabled Child Benefits Program. Under it a surviving adult dependent child of an insured worker may receive benefits if the child has a permanent and total disability originating before age 18. The child receives benefits beginning at the time of the retirement, disability, or death of the covered parent. It was originally estimated that there would be approximately 20,000 eligible beneficiaries under this amendment.[4] By the end of 1969 enrollment under this program reached the quarter million mark, of whom approximately 160,000 had mental retardation as their primary or secondary disability.[9]

Quite aside from the actual benefits made available to the individuals and the extent to which this has fostered continued maintenance of severely handicapped adults in the community, the unexpected experience of the Social Security Administration with these provisions has demonstrated, as almost no other program could have done, the extent of disability due to mental retardation in the noninstitutionalized adult population.

During the remaining years of the decade there was a general quickening of activity in most of the relevant HEW agencies and a steady increase both in appropriations and in elements grafted into the total program. The heightened interest was reflected in preparations for the 1960 White House Conference on Children and Youth, in which mental retardation was a major concern. It was significant also that many of the gubernatorial appointments to state delegations to that conference included lay as well as professional leaders in the mental retardation field.

By the time Congress adjourned in 1960 to engage in the campaign for its own and the President's election, it had raised the Department of Health, Education, and Welfare's commitment to research, training, and service on behalf of the retarded to nearly $94 million for the fiscal year 1961.

THE PRESIDENTIAL YEARS

During the late 1950s it was known, but seldom mentioned among the leaders in the mental retardation field, that former Ambassador Joseph P. Kennedy had a retarded daughter. It was also no secret that the family had, with the interested guidance of Cardinal Cushing, made significant contributions to enhance facilities for the care, training, and treatment of the retarded under Catholic auspices. Shortly before 1960, the Joseph P. Kennedy, Jr., Foundation shifted its emphasis from care and treatment to research into causes. Nevertheless, the personal reason for the family's interest was not publicized, and the professional and lay people working on behalf of the mentally retarded respected the family's apparent wishes for privacy in this matter, as they would have respected that of any other parents. As for the then Senator John F. Kennedy, he evinced no unusual interest in such legislation affecting the retarded as was then under discussion.

After his election as President, however, there were almost immediate stirrings. The first major move of the Kennedy administration that was to have significant consequences for the field of mental retardation was the proposal for the establishment of what became the National Institute of Child Health and Human Development, as one of the National Institutes of Health. This proposal emerged from the recommendations of the special Task Force on Health and Social Security mobilized during 1960 by Kennedy in anticipation of his election. It was chaired by Wilbur Cohen. The principal mover within the task force toward the idea of a "kiddie institute" was Dr. Robert E. Cooke, Professor of Pediatrics at Johns Hopkins, who had also been influential in shifting the Kennedy Foundation emphasis from service to research. An able physician and hard-driving administrator, Cooke is also the father of two retarded children.

Though the conception and birth of the new, institute was fraught with a number of complications, it was timely, because many specialists in pediatrics as well as obstetrics were eager to find among the National Institutes of Health one with which they could strongly identify. Moreover, as the acute diseases of childhood were one by one being brought under control, pediatricians were increasingly being confronted by the chronic disorders of childhood, particularly mental retardation and the related neurological conditions of cerebral palsy, "brain injury," epilepsy, and birth defects. Legislation creating the new institute was enacted in 1962 by the 87th Congress, after a legislative history that made it clear that both normal growth and developmental deviance, and especially mental retardation, should be major concerns of the new entity. This expectation is being fulfilled at the present time.[19]

Because the new institute was to focus on the developmental process rather than on a particular disease or organ, its structure, as developed under its first director, Dr. Robert A. Aldrich, represented a departure from the usual organization by subdisciplinary specialties. Since 1965 its extramural activities have been organized into programs. There are now five of which mental retardation is one. This program became the natural home of the research centers, construction of which was subsequently authorized by the Kennedy legislation of 1963.

During the early spring of 1961 after a 5-year effort, the Joint Commission on Mental Illness and Health, funded under the Mental Health Study Act of 1955, issued its final report, which was widely distributed under the title *Action for Mental Health.*[12] This study touched only incidentally on the problems of the mentally retarded and, indeed, gave little emphasis to the mental health problems of children generally. It was, however, to be the springboard for a major extension and reprogramming of the federal role in mental health.

Shortly after this the presidential decision was firmed up to appoint an ad hoc study group (quite differently constituted and funded than the Joint Commission) to consider the nation's responsibilities in research, training, and service related to the prevention and management of mental retardation. The idea was urged on the President by his sister, Eunice Kennedy Shriver. The President launched the 27-member President's Panel on Mental Retardation in October 1961. He met informally with its members in the Rose Garden and marked the occasion by issuing a formal statement whose opening paragraph spoke to the timeliness of the panel's mission:

> The manner in which our Nation cares for its citizens and conserves its manpower resources is more than an index to its concern for the less fortunate. It is a key to its future. Both wisdom and humanity dictate a deep interest in the physically handicapped, the mentally ill, and the mentally retarded. Yet, although we have made considerable progress in the treatment of physical handicaps, although we have attacked on a broad front the problems of mental illness, although we have made great strides in the battle against disease, we as a nation have for too long postponed an intensive search for solutions to the problems of the mentally .retarded. That failure should be corrected.[14]

The teamwork of the Kennedy family is well known, and as its numerous members began to take responsibility (officially or unofficially) for various aspects of the Kennedy agenda, it became apparent that Eunice Shriver would foster, on behalf of the President, the development of "a national program of action to combat mental retardation." She was named a "consultant" to the panel and played an active role in pressing for ever-increasing vigor in the panel's performance. Myer Feldman, a member of the President's staff and long-time aide to John Kennedy, was assigned to maintain liaison with the White House.

The President had originally given the panel 14 months to accomplish what appeared at the outset to be an impossible task. The time allowance was subsequently shortened to 11 months to accommodate the exigencies of the congressional calendar.

Following the second meeting of the full panel in December 1961, there ensued a period of intense activity under the leadership of Leonard W. Mayo, whose breadth of experience as chairman of the 1950 White House Conference on Children and Youth, as dean of a school of social work, and as executive of an influential private foundation active in supporting research in rehabilitation of the handicapped, stood him in good stead in a difficult and multifaceted assignment. He was energetically supported both by panel members and by a small but expert staff, recruited especially for this assignment. A suite of offices was made available in the main HEW building in Washington.

It had been apparent from the start in 1961 that the panel members did not plan to be rubber stamps either for one another or any other authorities. Nevertheless, an appropriate and productive interaction was developed between panel members, panel staff, and the leaders of the agencies that made up the Department of Health, Education, and Welfare, as of that time, each one of whom had a significant contribution to make, consistent with its particular mission in the health, education, and welfare field. Technical assistance was also sought from a variety of nongovernmental sources and especially from NARC and the American Association on Mental Deficiency (AAMD), the national voluntary and professional organizations, respectively, in this special field.

Exceptional indeed was the extent of participation and involvement of panel members in the process of assessment of need and projection of proposals for solution. The members were organized into six hard-working task forces. They traveled, met, conferred, held public hearings, inspected the best European facilities, gathered into their councils innumerable experts, drafted, redrafted, debated, and finally condensed their convictions into some 97 recommendations. The report was submitted by the full panel to a receptive and inquiring President on the morning of October 16, 1962, in the midst of the as yet unannounced Cuban missile crisis.

The panel members had recognized from the beginning that the ultimate fate of their mission would rest not alone with the President, but with the executive departments, with Congress, with governors and legislatures, and ultimately with the public. The panel, therefore, had sought to give appropriate publicity to its work in progress through public hearings and through the preparation of a Chart Book dramatizing its findings.[22] Both during and following their official tour of duty, Members of the panel responded to many opportunities to speak of its work and of the broad problems which gave rise to it.

Shortly after the first panel meeting, the President and Mrs. Shriver received at the White House the 1961 poster girls of the NARC. Sheila McGrath of Arvada, Colorado, a victim of uncontrolled phenylketonuria, had suffered irremediable damage to her brain and was profoundly retarded. Her younger sister, Kammy, however, though exhibiting the same metabolic defect, had been permitted to develop normally because, in the interval before her birth, science had developed means for early detection of phenylketonuria and for preventive intervention through use of a synthetic diet. The visit of the two girls and their parents was well covered by the press and also made a deep impression on President Kennedy, who referred spontaneously to this hopeful example on several later occasions.

Mrs. Shriver (and the entire family) later made an important personal contribution to public awareness by authoring an article that appeared in September 1962 in the *Saturday Evening Post.*[26] In it, she provided, for the first time, a full and frank public account of the Kennedy family's personal involvement. Into the story of the President's retarded sister, Rosemary, Mrs. Shriver wove a wealth of information about new developments in the field, and conveyed a sense of action and hope that helped to prepare the way for acceptance of the panel's recommendations when they were made public shortly thereafter.

This was followed by another event executed in the best Kennedy style and calculated to focus attention on the drama of mental retardation during the necessary period of incubation following submission of the panel report. At a gala dinner in Washington on December 6, 1962, attended by many members of the Cabinet, Supreme Court, Congress, and the Diplomatic Corps, as well as by leaders in the mental retardation field and an especially selected group of medical students, the President presented the Kennedy Foundation's first International Awards in Mental Retardation.

Adlai Stevenson, then U.S. ambassador to the United Nations, was master of ceremonies, quipping his way lightly out of the awkwardness created a few days earlier by a magazine feature article reporting an alleged difference between himself and the President during the Cuban crisis. The spontaneous Kennedy wit also was in evidence that night. A minor miscue caused the President to omit one step in the ceremony of presentation. After whispered prompting by Sargent Shriver, the foundation's executive director, the President remarked: "Now you see how this administration is really run."

Meanwhile the administration's "no nonsense" machinery was carrying forward that enlargement of its effort for which the panel had set the stage, particularly in the Department of Health, Education, and Welfare. Effects of the ongoing process of interaction between the panel and HEW during 1962, the year of the panel's activity, were twofold: (1) The department was itself faced with the necessity for organizing to meet the challenges and demands of the panel. This resulted in a revitalization of the coordinating machinery within the department and specifically in the formation of a Secretary's Committee on Mental Retardation, chaired by Mr. Luther W. Stringham, representing the Office of the Secretary. (2) Those agencies who saw for themselves an increasingly creative role in developing some aspect of the comprehensive program for mental retardation were able to plan ahead during the summer and fall of 1962 and thus to gain valuable time in initiating proposals for new or expanded programs to implement the recommendations that the panel was in the process of drawing up.

Adherence to this compressed and rigid time schedule in the completion of the work of the panel was extremely valuable in securing a prompt response both by the executive branch and by Congress. Though the panel's report was yet to be finally edited and printed when presented to the President in October 1962, the recommendations nevertheless were available for use in preparing the President's budget for fiscal 1964 and the legislative program for 1963, both of which were formulated in the fall of 1962. Increases in existing programs of the Public Health Service, Vocational Rehabilitation Administration, the Welfare Administration, and the Office of Education were promptly recommended by the Department of Health, Education, and Welfare and approved by the Bureau of the Budget.

The drafting of new legislation also was promptly begun, and by the time the panel report was in print the following February (1963) three major pieces of legislation addressed to five major recommendations of the panel were in the hopper. At the same time, legislation based on the administration's response to the 1961 report of the Joint Commission on Mental Illness and Mental Health was also introduced. Both were heralded by the first presidential message to Congress on mental illness and mental retardation, delivered on February 5, 1963.[13]

Meanwhile the President had implemented one panel recommendation that had not been included in the panel's printed report but was conveyed directly to the President. It was suggested to him that, to ensure continuity in maintaining the thrust behind the panel report and as a symbol to all of the direct commitment of the administration, a temporary position should be created in the immediate office of the President, whose incumbent would have a variety of responsibilities for bespeaking the President's interest to governors, universities, civic leaders, professional groups, and communications media. The holder of this position was also seen as in a position to kindle interest in any federal department that might fail on its own initiative to recognize the role it could and should play on behalf of the retarded. The Department of Defense, for example, had not always recognized the problems it created for those servicemen who have retarded children.

Accordingly, the President, in December 1962, appointed Dr. Stafford Warren as special assistant to the President for mental retardation. Dr. Warren had been vice-chancellor for medical affairs of the University of California at Los Angeles and was largely responsible for developing its successful medical school complex. A man with broad interest and experience, he was at the time of his appointment on the verge of retirement. He was given offices and small staff in the Executive Office Building and soon governors, business leaders, and university presidents began to receive a new kind of communication from the White House. While the Department of Health, Education, and Welfare was grappling with the many panel recommendations for which it clearly must assume major responsibility, Dr. Warren was tickling the conscience and enlisting the interest of numerous other agencies, organizations, and individuals, both public and private.

While detailed accounts of the accomplishments of the President's assistant for mental retardation have not been written, the main contributions of this effort can be identified:

1. The existence on the White House staff of a senior man with sole responsibility for mental retardation served notice on the entire federal establishment that this was problem that commanded presidential interest and top policy attention. On the Washington scene the implications of. such proximity to the White House staff, the Bureau of the Budget, and the President himself does not pass unnoticed. In the difficult transition following the death of President Kennedy the retention of this office was of particular importance in indicating an intention to provide continuity of efforts on the part of the new President.

2. Dr. Warren and a series of deputies provided to him for relatively short periods of duty were unsparing of themselves in traveling all over the nation, responding to a great many invitations to confer with governors, state legislators, and government personnel and to address scores of meetings of parents, civic leaders, and professionals. The contribution of these activities to public awareness doubtless was great.

3. The President's special assistant was provided with sufficient funds to make possible periodic meetings of an ad hoc advisory committee of distinguished persons. Members of this group provided ties with members of the former President's panel, the Kennedy Foundation, AAMD, NARC and other individuals and groups. The meetings provided a place for the exchange of views and were another way in which the word was passed that the administration cared about the mentally retarded.

Dr. Warren and his staff also carried out a number of significant special assignments. For example, his office became the secretariat for the Advertising Council's campaign of public information concerning mental retardation launched during 1963 and continuing through 1966. The 1964 material featured President Kennedy. The 1966 material underlined President Johnson's interest. The campaign was jointly supported by the Department of Health, Education, and Welfare, the Joseph P. Kennedy, Jr., Foundation, and NARC. It was well complemented by a major project of the U.S. Junior Chamber of Commerce. These efforts, like most of those in which Dr. Warren's office participated, were related to one or more of the specific recommendations of the President's Panel. The panel had, among other things, found public awareness of the problem of mental retardation reprehensibly lacking.

Another "homeless" panel recommendation received attention when Dr. Warren reviewed the report of its task force on the law. The report stressed the neglect of "the mentally retarded and the law" as the subject of objective study. Dr. Warren's powers were, of course, limited, but he could encourage interaction between scholars and their universities, on the one hand, and funding agents, public or private, on the other. In this instance he enlisted the interest of the National Law Center of George Washington University with the result that a major empirical study on the mentally retarded and the law was initiated with support from NIMH. A comprehensive report of the findings of this study is expected to appear in print in 1972.

Dr. Warren was continued in office by President Johnson through the full period originally contemplated, and when he resigned on July 1, 1965, he could look back on a remarkable period of tragedy and triumph, frustration and fulfillment.

One of these moments of fulfillment was achieved with the signing of the first bill implementing the Kennedy program to combat mental retardation—Public Law 88-156. Among those present were many parents and other leaders in national and state associations for retarded children who had gathered in Washington for the NARC convention in October 1963. Immediately after the signing at the White House, President Kennedy addressed the opening luncheon of the convention and presented the NARC Distinguished Service Award to Dr. Richard L. Masland, Director of the NINDB and shepherd of the "collaborative perinatal project." In his remarks, the President praised the association for its leadership and referred to his encounter with Kammy and Sheila McGrath, the phenylketonuria children, 2 years earlier, and of the hope through research that Kammy's salvage represented. He also spoke feelingly of parents who "frequently must face decisions at hospitals of what therapy should be adopted to preserve a child's life knowing that the therapy may bring about mental retardation or blindness." None of his knowing listeners who had followed a few weeks earlier the accounts of his own decision to have his infant son, Patrick, treated in a hyperbaric oxygen chamber could miss the poignancy of this allusion.

The 1963 Legislation

The bill signed on this occasion authorized funds for grants to the states to begin comprehensive mental retardation planning of their own on a coordinated interagency basis. It also authorized funds for special maternal and child health grants to improve care, especially prenatal care, to women who, for economic or social reasons, are unlikely to receive adequate prenatal care and whose infants are, therefore, according to all statistics, especially at risk of mental retardation or some other developmental disorder. In addtition, it carried increases in the authorizations for grants to the states for maternal and child health and crippled children's services. Because these increases were enacted as part of a mental retardation package there was an implication that a portion of the increase would benefit retarded children. This is the origin of the legislative and administrative earmarking that has been faithfully honored in succeeding years, largely at the insistence of Dr. Arthur Lesser, who has headed the federal maternal and child health program throughout this entire period.

The second "mental retardation" bill of 1963 pertained to the construction of facilities for the "diagnosis, treatment, training and custodial care" of the mentally retarded (including "clinical" facilities affiliated with universities for the purpose of training personnel) and for the construction of comprehensive research centers in mental retardation. This bill was later combined with the community mental health centers bill to form a single composite construction bill, to which was also attached, as Title III, still another bill, originally introduced separately, to extend and enlarge the 1958 legislation on the training of personnel in education of the mentally retarded. The two resulting package bills made their way through a sympathetic but critical Congress, in time to be signed by President Kennedy in October 1963.

Because the two pieces of legislation signed by the President shortly before his death were to have major continuing impact, their history, potentials, and limitations are worth recording here.

Though launched in the name of mental retardation, it must be recognized that the program of projects (authorized by Public Law 88-156) for improving maternity and infant care in high-risk areas is basically a program of intervention in the cycle of poverty, and indeed it was subsequently complemented by the child health care provisions included in Public Law 89-97, the omnibus medicare bill of 1965. Some mental retardation may in fact be prevented by both these types of undertakings, but surely only as one result of a program that has had a multifaceted impact on infant mortality and morbidity generally.

The same bill's provision for mental retardation planning grants to the states, on the other hand, though much more limited in dollars (total authorized appropriation for a 2-year period amounting to $2.2 million), was more highly targeted and has obviously exerted a very considerable leverage specific to retardation in the 53 jurisdictions that were to take advantage of it. With nucleus grants that, in many cases, amounted to no more than $30,000 per state, an 18-month assessment, coordination, planning, and public education activity was launched in the respective states which, in the more successful at least, paralleled within the states the impact that the President's panel had nationally. The 1965 medicare bill included an amendment authorizing a total of $5.5 million in funds expendable up to July 1968 for the strengthening of the coordinating mechanisms at the state level and for the central activities necessary to implement the comprehensive mental retardation plans as formulated. A variety of instructive, indigenous, and innovative ideas were built into the state plans. As one result there will be within the next decade an opportunity to compare a number of different ways of organizing services for the mentally retarded at both the state and community levels.

The three bills that were combined to make Public Law 88-164 derived from quite different premises and were formulated by different agencies, within the Administration, for different purposes.

The bill that eventually became its Title III was frankly an education bill and was designed to extend the old Public Law 85-926 and to combine it with Public Law 87-276, on education of the deaf, so that, under it, teachers and leadership personnel might be prepared to serve in any of the major areas of special education. The new legislation increased the authorization for appropriations accordingly. In addition it authorized very modest sums to be appropriated for demonstrations in special education. It is significant to note that all of its provisions were emphatically oversubscribed during 1964-1965, with the result that major increases were authorized by legislation in 1965.*

As an education bill, the teacher training proposal went in the House to the Committee on Education and Labor, while the two construction bills, being "health" measures, were assigned to the Committee on Interstate and Foreign Commerce. In the Senate both bills went to the Committee on Labor and Public Welfare, which handles education and rehabilitation as well as health legislation. An impasse threatened in the House, however, for whereas the previous chairman of the House Committee on Education and Labor had blocked much education legislation out of resentment for

the rapid advance of federal action in support of civil rights, the 1963 incumbent made it clear that he would conduct a personal sit in against administration education legislation to protest what he considered the undue delay on the part of the Kennedy administration in pushing civil rights. Because of the benefits that would accrue to mentally retarded and emotionally disturbed children, and because of the tie in with the panel report, the powers in the Senate committee decided to class the teacher training bill in special education as "health" legislation. It thus came before the Senate subcommittee on Health, where it was combined with the two construction bills on mental retardation facilities and mental health centers, respectively.

Parts A, B, and C of the original mental retardation facilities construction bill (which eventually became Title I of Public Law 88-164), dealt respectively with comprehensive research centers in the biomedical and/or behavioral sciences related to mental retardation, with university-affiliated service facilities (UAFs) for use in the training of personnel, and with facilities for the diagnosis, treatment, training and "custodial care" which might be developed under state plans. For Part C, money was made available on the basis of allotments to the states. The essential underlying rationale of this part of the legislation was the need for *new* authority if the range and types of facilities needed by the retarded were to be constructed. The limitations of the Hill-Burton Act to health and hospital facilities had, as earlier history had clearly demonstrated, placed outside its pale those needed facilities for the retarded that could not be classed as primarily medical. Dr. Jack Haldeman, director of the Division of Hospital and Medical Facilities, U.S. Public Health Service, had become convinced of this need, and his agency actively sought the new authority.

The panel had emphasized the need for new substantive legislation in the area of construction for the retarded and had indicated that such legislation should increase the latitude and broaden the options available to states and communities, as well as providing substantial categorical allotments. The panel report especially stressed the shortage of modern residential facilities and the need for day-care facilities for the retarded of various age groups.[23] It could have been anticipated that the sponsors of such services would face financial problems quite different from those of community hospitals and that patterns of federal matching and state and community planning that had served in the hospital field would not necessarily be most appropriate in the new area. Nevertheless, for the Public Health Service, the Hill-Burton Act was a convenient and familiar legislative model and it was used in large measure for the community portions of both the mental health and mental retardation acts.

There had also been doubt as to whether the panel's recommendations for comprehensive interdisciplinary research centers could be successfully and comfortably implemented under the existing Health Research Facilities Act. This doubt arose, in part, because it was desired to include research in fields that are health related only in the broadest sense, but even more because it was felt that the desired organizational concepts involved in "mission-oriented" research centers, being somewhat alien to the traditional structure of most universities, might need to be sold with the extra inducement of more favorable federal matching (75%).

Implementation of parts A and B was subsequently accelerated by the Kennedy Foundation, which offered the required nonfederal construction funds for several research centers. The foundation also provided planning money for several "UAFs" to enable them to seek grants under part B.

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*As an important by-product of this legislation a new Division on Education of the Handicapped was created in the Office of Education in January 1964. It flourished during a brief but vigorous period with Dr. Samuel Kirk as its director.

Unlike the mental retardation legislation, the Community Mental Health Centers bill (which eventually became Title II of the omnibus act) had been drafted, not out of the need for broadened authority but out of a conviction that official and voluntary efforts at the state and local levels must be rechanneled through the inducement of major funding specifically directed toward the promotion of "community psychiatry" and the development of mental health facilities having a particular character. Such facilities could have been developed under existing Hill-Burton authority, but it was clear that local initiative would not move rapidly in this particular direction unless increased funds were specifically so channeled.

The harnessing of the two just mentioned bills in tandem has tended to obscure the rather different objectives that gave rise to them and has encouraged in some quarters the assumption that there is greater implicit parallelism than was in fact intended.

This tripartite bill, when created and passed by the Senate under the skillful leadership of Senator Lister Hill, was referred in the House to its Committee on Interstate and Foreign Commerce, chaired by Congressman Oren Harris of Arkansas. It was this committee that struck out the original staffing provisions from the mental health centers title of the bill. The bill was curtailed also in other ways, but considering the nature of the opposition, its final passage reflected hard work and determination, as well as statesmanship on the part both of Congressman Harris and his subcommittee chairman, Congressman Roberts.

During 1965, the community mental health centers title was amended to provide funds for paying the salaries of professional and technical personnel in community mental health centers. The new act stipulated that these project grants for initial staffing should decline rapidly over the first 51 months of the project's existence, on the assumption that during that period income from patients' fees, health insurance (including medicare), and other public and private local resources, would be stabilized at a point at which the center could be sustained without direct federal subsidy. This medical model seemed particularly unsuited to mental retardation facilities whose services generally do not come under hospital and medical insurance definitions and whose clientele is not the rapidly revolving one anticipated for the community mental health centers. Therefore, NARC did not seek a parallel provision in 1965, preferring to work with the administration in developing a more suitable pattern for support of needed innovations in the delivery of services to the retarded, both in and out of special facilities. This particular gamble of postponing immediate gratification for a greater gain in the future did not pay off, however.

Legislation to amend and extend the Vocational Rehabilitation Act was introduced early in 1961, before the panel was activated, and was pending during the life of the panel. Panel members expressed support for its provisions, but other conflicting forces produced a congressional stalemate in the 88th and 89th Congresses. At that time the basic authorizations for support to the states did not expire, and it was the custom to establish the allotment base in the annual appropriation bills. Hence the pressure attendant on expiration of major authorizing legislation was lacking in this case. The 1963 version of the bill incorporated some panel recommendations, but it remained for the Johnson administration to see legislation through to enactment.

This delay was occasioned by a variety of considerations, including the perennial problem of a formula for allotment to the states and for differential matching. The act, as of that time, used the Hill-Burton formula. This was exceptionally favorable to the states of the Deep South. Another factor, which in retrospect assumes greater importance to the mentally retarded, was the opposition to the so-called independent living provisions of the 1961 bill. These provisions were later dropped. Their purpose was to extend appropriate rehabilitation services to persons who were not "feasible" under the existing act, i.e., those so severely handicapped as to be unlikely candidates for placement in substantial remunerative employment, but who could be assisted to achieve a higher level of personal independence and self-care. Such assistance could be expected to reduce the economic burden of their care as well as achieving for them a greater sense of dignity and satisfaction in living. Opposition to these provisions came primarily from the welfare establishment whose members saw these objectives as appropriate to their own social services mission under the heading of "reducing dependency." Wilbur Cohen and others wiio were, in 1961, preparing the now famous 1962 welfare amendments to the Social Security Act were not anxious to lose one of the more appealing selling points for expanding social services to disabled adults receiving public assistance.

The long-range significance of this contest between competing bureaucratic empires lies, for the clientele, in the difference between the basic premises of the two systems of service. Vocational rehabilitation operates on the "universal" principle that services are to be available to all persons with a remediable handicap without a means test, whereas federally aided social services (as defined in the welfare titles of the Social Security Act) are provided only to past, present, or "potential" welfare clients or applicants, thus limiting eligibility to disabled persons who also meet welfare criteria.

Because one of the purposes of federal aid is to create resources where none exist and because disabled persons who may not meet the welfare eligibility tests frequently do not have access to the services they need to improve their functioning, this kind of arbitrary segregation by economic status is both inequitable and inefficient. It has created a situation in which a mildly and even a moderately handicapped person receives special education, vocational training and rehabilitation as a matter of right, whereas a more severely disabled person is eligible for federally aided services to alleviate his dependence on others only if he (or his family) is deemed to be at the poverty level.

Had the independent living proposals of 1961 been added to the Vocational Rehabilitation Act at that time and been appropriately funded, it seems very likely that the status of services to severely disabled youth and adults could have been much more rapidly advanced than they were by the end of the decade.

Administrative Action within the Principal Departments

The legislative developments from 1963 onward were accompanied and indeed fostered by certain further executive and administrative actions of considerable significance. The White House Conference on Mental Retardation was organized jointly by HEW and Dr. Warren's office; it was held at Airlie House in Warrenton, Virginia, during September 1963. President Kennedy addressed it by telephone. Speakers included a remarkable assemblage of U.S. commissioners of education, welfare, rehabilitation, and the Public Health Service. To the conference were invited the key officials in state government, who, in the eyes of their respective governors, were most concerned with the various aspects of the state mental retardation programs as they would now emerge. Leaders of NARC and its state member units were invited observers. The conference served both to alert the participants to the significance of the new federal legislation and to kick off the federally aided comprehensive state planning in mental retardation.

Within the Department of Health, Education, and Welfare, the Secretary's Committee on Mental Retardation was activated, as mentioned earlier. This committee has continued and, though its vitality as a committee has ebbed and flowed, the persistence of its two staff members in gathering, synthesizing, and disseminating information has contributed significantly to the effective utilization of federal resources as well as to the visibility of the overall program. Its annual summary publications, *Mental Retardation Activities of the Department of Health, Education, and Welfare,* are in themselves an important documentation of growth and progress of federal activity.[24]

One new agency, at the time the only one devoted exclusively to mental retardation services within the federal establishment, was created. It started in December 1963 as the Mental Retardation Branch of the Division of Chronic Diseases of the Bureau of State Services of the U.S. Public Health Service, Department of Health, Education, and Welfare. It grew out of the mental retardation activities of the Neurological and Sensory Diseases Branch of the same division, which in turn had come into being about 2 years earlier as an instrument to expedite the application of new research findings generated by NINDB. The first and most immediate task of the new branch was to administer the mental retardation planning grants, under Public Law 88-156, but it also brought with it a small but useful piece of public health project money ($0.5 million), which it used very effectively to promote demonstrations and short-term professional training with emphasis on coordination and on improvement of health-related services to the retarded.During 1965 the House Appropriations Subcommittee indicated its hopes for this small new arm by providing $4.5 million, thus nearly tripling the appropriations that the administration had requested for its projects for fiscal 1966. It was only later that the branch also assumed responsibility for the construction programs under parts B and C of Public Law 88-164.

The Division of Hospital and Medical Facilities (DHMF) in the Public Health Service had, after all, been the proponent and principal architect of the community facilities portion (Part C) of the mental retardation legislation and had made the necessary preparations to administer it, beginning with the 1965 appropriation of $10 million. However, it became increasingly apparent that state planning for construction (as required under Part C) must be related to comprehensive planning as administered by the branch and that in any case there was logic in bringing together in one agency certain service related programs uniquely specific to mental retardation. The branch might thus hope to develop the mass, visibility, and coherence of purpose necessary to exert effective quantitative change in the field. Thus it was that on January 1, 1967 the funds, responsibility, and staff associated with these construction programs were moved within the Public Health Service from DHMF to the Mental Retardation Branch, which was simultaneously raised to Division status within the Bureau of State Services. Later in the same year the programs went with the Division out of PHS to the newly organized Rehabilitation Services Administration created under the umbrella of the Social and Rehabilitation Service.

The facilities that were to be built in conjunction with universities under Part B were conceived as "clinical," i.e., service, facilities that would serve the professional training programs as models of service and settings for practicum, much as teaching hospitals serve the medical schools. The lack of such affiliated facilities and the physical and social distance between universities and the major residential institutions housing retarded children and adults had been deplored by many knowledgeable people not only during the panel deliberations but as far back as the Masland study.[14] In the development of the administration's 1963 legislative proposals authorization for construction of these university-affiliated facilities had been spun off (largely at the insistence of Dr. Cooke) from the authorization for other community facilities in order to assure direct access by interested universities to the federal funding agency without interposition of the state agency-state plan requirements built into Part C. As originally conceptualized, the UAFs' mission did not include research more than incidentally. They were to give service on an exemplary basis and to train for service. Nevertheless, several of the universities that were early candidates for research center grants were equally interested in training "physicians and other needed personnel" for specialized practice; to the mental retardation proponents in these universities, as well as to their colleagues within HEW, the university, not the mission, seemed to be the common denominator. Consequently, the director of the National Institute of Child Health and Human Development (NICHD), to which the research center program under Part A had been assigned without contest, made a strong pitch to secure Part B also. This decision hung fire until the spring of 1964 when it was finally decided in favor of bracketing with the community construction program.

It was foreseen from the start that universities would be somewhat reluctant to build such facilities unless they could have some assurance of help with operational costs. Informal assurance was given that, by the time construction was completed, sources of federal assistance would be opened up. Unfortunately, for a variety of reasons, the expectations built on these conversations were only partially fulfilled in the years that followed. Rightly or wrongly, this default continued to be seen by some academic sponsors as a consequence of the failure to tie down the UAFs as part of the NICHD responsibility.

Another piece was added to the branch's aggregate in late 1966 when it received by transfer the responsibility for the mental retardation portion of the hospital improvement and hospital in-service training programs which had been developed by NIMH. The first grants were awarded by NIMH in fiscal 1964. Under this program each state hospital and institution for the retarded was eligible to apply for a project grant to develop constructively some aspect of residential care. Awards could run as high as $100,000 per year for 10 years. Along with these, the same institutions were eligible for grants of up to $25,000 annually for in-service training of personnel, especially those having direct care of the retarded residents. At the outset the program was planned to escalate by the mid-1960s so that all state institutions could be funded on receipt of acceptable project proposals; unfortunately, funding was leveled off prematurely at less than half the anticipated level.

By fiscal 1967 the Division was spending more than $42 million for its 5 newly assembled component programs.

The activities of the President's Panel on Mental Retardation produced stirrings also in agencies other than HEW. The Department of Labor became more aware of the contribution of mental retardation to unemployment.[29] Its manpower agency accepted an explicit role. The Department of Defense surveyed the problem of mental retardation among the dependents of servicemen. The Department of Interior fostered the use of outdoor recreation facilities by the retarded. The Economic Opportunity Act provided that VISTA volunteers could be assigned to federally aided programs for the retarded, thus implementing another Panel recommendation. Neighborhood Youth Corps recruits and federally funded college work stody students have been employed in serving the retarded. The relationship of Project Head Start to reduction of retardation presumed due to cultural deprivation has not been overlooked. Also out of the Office of Economic Opportunity came the eminently successful foster grandparent program under which impoverished older persons are recruited and paid to give "grandmothering" and "grandfathering" to institutionalized children, many of them retarded.[10]

The President's Committee on Employment of the Physically Handicapped, from 1960 on, began to step up its activities on behalf of the mentally retarded and "mentally restored." In due course the word "physically" was dropped from its title at presidential behest. It was an address by Mrs. Shriver to this body that sparked action by the federal Civil Service Commission to open appropriate employment to qualified mentally retarded adults.

The Mentally Retarded as Members of the Great Society

The year 1964 was, for many reasons, a year of consolidation, but 1965 saw further "giant steps." Legislatively speaking, the mental retardation program was significantly advanced as an integral part of measures aimed at the realization of the Great Society.[3]

After a four year delay, revision of the Vocational Rehabilitation Act was finally achieved. Rehabilitation is a rapidly developing field, and it was not surprising, therefore, that when a new administration bill was introduced in 1965, it reflected additional advances in thinking as compared to the unsuccessful bills of 1961 and 1963. It was still further developed and liberalized during its passage through Congress. Representative Edith Green and members of her Special Subcommitte on Education took an active role and left their stamp on the bill. Senator Hill handled it with his usual consummate skill in the Senate. The amendments broadened the variety of modalities for the improvement and expansion of sheltered workshops for training and long-term employment. Technical consultation, construction funds, training stipends, and initial staffing were among the instruments added. The bill borrowed liberally and imaginatively from precedents set by previously successful legislation in related fields such as the Community Mental Health Centers Staffing Act of 1965. The bill also broke ground in authorizing construction of community residences for retarded adults undergoing rehabilitation and in extending the permissible period of evaluation of mentally retarded and other severely handicapped persons. It became Public Law 89-333 in November 1965.

In addition to these amendments, and the Hill-Harris amendments extending and amplifying the program for training of personnel in special education, (tied into the bill on community mental health centers staffing—Public Law 89-105), there were important provisions affecting the mentally retarded both in the medicare bill (Public Law 89-97) and in the Elementary and Secondary Education Act of 1965 (Public Law 89-10). The former not only provided for implementation of state level mental retardation planning, but also gave authority (under what is now Section 511 of the Social Security Act) for the Children's Bureau (later Maternal and Child Health Service) to share in the operating costs of university-affiliated facilities for the retarded to the extent that they might be contributing to the training of personnel for the health care of "crippled children, especially mentally retarded children." Other provisions less specific but equally important to the retarded: (1) increased the benefits payable to social security beneficiaries, including the adult disabled children of formerly covered persons, (2) laid the groundwork for medical assistance to be paid to or on behalf of needy persons requiring skilled nursing care in state and private institutions for the retarded, (3) permitted social security trust funds to be used for the rehabilitation of beneficiaries, (4) somewhat increased the amounts that can be earned by a permanently and totally disabled person without reducing his assistance payments, and (5) tackled the serious sociolegal problem of "protective payments" for persons who are not able to manage wisely the small sums to which they become entitled under social insurance and assistance programs.

The Elementary and Secondary Education Act of 1965, thanks to Senator Morse of Oregon, Senator Javits of New York, and Senator Prouty of Vermont, made it clear that handicapped children, including the mentally retarded, were to be considered "educationally disadvantaged" for the purposes of the bill and that projects for improving education of the handicapped would, inter alia, be eligible under several titles of the bill. A later amendment proposed by Senator Robert Kennedy and supported vigorously by Congressman Hugh Carey, was incorporated in Public Law 89-313. It expressly includes the school-age populations of state residential institutions and state-supported private schools as among the disadvantaged eligible for project aid. Similarly, support for teacher training under the Higher Education Act of 1965 was also expressly extended to include teachers of the handicapped.[16]

Much of the credit for final formulation of these various programs, especially in health and social welfare, as well as their interpretation to Congress under both Kennedy and Johnson, must go to Wilbur Cohen, who was appointed assistant secretary for legislation in HEW by Kennedy. In the spring of 1965 he became Johnson's undersecretary and finally Secretary of HEW in 1968.

An inconspicuous provision in the 1965 amendments to the Immigration Act for the first time enabled retarded would-be immigrant children to accompany or join their close relatives in this country under certain stringent conditions. Its enactment is a complex bureaucratic and legislative story. Suffice it to say that, prior to 1965, the immigration laws absolutely excluded persons with mental disorders, including the mentally retarded and even the recovered mentally ill, from entering the United States as permanent residents. As a by-product it placed serious difficulties in the way of temporary visits. One of the numerous modifications to the Immigration and Nationality Act proposed by President Kennedy and by Robert Kennedy as his attorney general, and subsequently by President Johnson, would have permitted the admission of a close family member, despite some mental disorder. The House Committee on the Judiciary struck out the clause, however. Only well-timed action on the floor of the House by Congressman Fogarty, supported by Congresswoman May of Washington and others of both parties, together with subsequent efforts by Senator Edward M. Kennedy in the Senate Judiciary Committee saved this unpublicized amendment within a major bill. The restored provisions opened the door by a small crack to the mentally retarded and recovered mentally ill. It represented the last of the mental retardation carry-through items in the Kennedy agenda. The bill became law on October 3, 1965.

THE END OF AN ERA

The overall effect of 3 years of executive-legislative action (1963—1965) was to enhance markedly the expectations as well as potentials for activity and impact by the federal government in promoting research, professional training, planning, and prevention in relation to mental retardation. These years also brought partial redress of discrimination in respect to personal entitlement of the retarded to social and educational benefits. With respect to direct services, however, the instruments for major impact were limited to rather selected areas.

The interested professional and lay constituency approached 1966 with considerable optimism that the next logical steps might be taken in 1966 to fill in the more glaring gaps in the spectrum of services. One source of optimism was the courageous manner in which Vice-President and Mrs. Humphrey had responded to their grandchild, Vicky Solomonson, whose birth had coincided with the Johnson-Humphrey election victory of 1964. Following the election, Johnson appeared willing to carry forward the Kennedy objectives, albeit with his own personal and legislative style. All these hopes were to be dashed early in 1966, when, by a decision at the White House level, all mention of administration support for expected legislation to extend and enlarge Public Law 88-164 to cover costs of staffing new services for the retarded was deleted from President Johnson's health message to Congress. This little-known event proved to be a turning point in a number of ways. It became increasingly apparent thereafter that the Vice-President was under wraps on all subjects including this one. Planned escalations in funding of programs initiated during the first half of the decade began to be curtailed. Even the eventual appointment of a new ongoing President's Committee on Mental Retardation did not lend complete credibility to what had been earlier seen as a continuing presidential commitment to a cause that enjoyed bipartisan support in the Congress.

Legislative leadership reverted to the Congress, which in 1966—1970 wrote another chapter to this story, against a backdrop of kaleidoscopic changes in the social scene. This latest chapter will be presented in a subsequent essay.

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